

Cranfield University

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**Patient knowledge and its role in the management
of coronary heart disease.**

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ABSTRACT

This study examines the role that patient knowledge plays in helping patients to manage a chronic condition such as coronary heart disease (CHD). It asks two questions: firstly, what sources do CHD patients use when seeking knowledge about their condition, and what are their reasons for doing so? Secondly, do patients, in the course of managing their CHD, generate knowledge about the condition and its treatment? The study is based on a qualitative analysis of semi-structured interviews conducted with 34 patients with diagnosed CHD. It uses the grounded theory method.

The study makes a contribution to knowledge in a number of areas. Firstly, it shows that the patients interviewed obtain health information from a wide variety of sources, but prefer knowledge derived through personal interaction; their knowledge-seeking appears to be influenced by the quality of their relationship with their GP.

Secondly, it shows that these patients seek three distinct *types* of knowledge from different sources: expert knowledge from GPs and consultants; personalised practical knowledge from nurse specialists and cardiac trainers; 'folk' or common sense knowledge from close friends, family and other patients.

Thirdly, it identifies two examples of patient-generated knowledge that could help improve CHD management – firstly, the understanding that underpins patients' self-generated home-made health records; secondly, the patient embodied understanding that their health knowledge does not determine their health behaviours where the benefits of such knowledge are deferred.

Fourthly, the study develops a theoretical model to explain how individual patient observations and practices can be converted into potentially valuable organisational knowledge.

Finally, four areas are identified where health benefits may be obtained through improving current knowledge management interventions aimed at CHD patients: by using technology to assist patient involvement; by personalising cardiac rehabilitation; through the reconfiguration of long-term clinical pathways; and through better co-ordination of treatment across primary and secondary care, and across clinical specialities.

As this is a qualitative study, the findings are theses, grounded in the words and actions of the patients studied. However, the new light shed on aspects of patient knowledge and the associated theoretical developments can help guide future study and encourage a re-evaluation of the effectiveness of knowledge management interventions aimed at chronic disease patients.

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An especially big kiss goes to my daughter Maeve for being patient when necessary and to my husband John for his invaluable comments and moral support.

This work is dedicated to my mother Margaret, who could have added stories of her own.

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NOTATION

CRP	Cardiac Rehabilitation Programme
DoH	Department of Health
EPP	Expert Patient Programme
IHCA	Interactive Health Communication Application
KM	Knowledge management
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PCT	Primary Care Trust
RCT	Randomised Controlled Trial

CHAPTER 1 | CORONARY HEART DISEASE AND THE HEALTHCARE CHALLENGE

1. INTRODUCTION

This work investigates the role of patient knowledge in the management by patients of their coronary heart disease (CHD), one of the UK's most prevalent chronic diseases. The study seeks the answer to two questions: firstly, what sources do CHD patients use when seeking knowledge about their condition, and what are their reasons for doing so? Secondly, do patients, in the course of managing their CHD, generate knowledge about the condition and its treatment?

The investigation focuses on two aspects of patient knowledge: patient knowledge-seeking and patient knowledge generation. The work is based on a study conducted with CHD patients who live in Camden, North London.

In order to assist an understanding of the study that follows, the medical background and policy context relevant to the enquiry are described at the outset. To this end, this chapter sets out a definition of chronic disease: the different phases in a chronic disease are explained, and its anticipated rise over the next decades is accounted for. The causes and prevalence of CHD are set out, along with the development of its medical management and the importance of the management of modifiable risk

factors. The penultimate section explains why the study is relevant and looks at how it ties in with broader trends in NHS health policy.

The chapter concludes by summarising how the thesis that follows is structured, in order to help orient the reader.

2. THE ESCALATION IN CHRONIC DISEASES

Chronic diseases are non-infectious, long-term conditions that at present can only be contained rather than cured – the most notable are coronary heart disease, hypertension, diabetes I and II, cardiovascular disease, stroke, some cancers and chronic respiratory disease. They develop slowly over time and tend to lead to long-term health impairment and premature death before the age of 75. Such diseases already take a heavy toll on the UK population: it is expected that the UK will face an unprecedented chronic disease epidemic in the next few decades and that this will make a dramatic impact on primary and secondary healthcare provision. The number of people with chronic disease is expected to increase two to threefold in the next 30 years (Khaw, 1999) and the two key factors that account for this major change in population health are an ageing population, coupled with unhealthy lifestyles.

Even though chronic disease is generally built up over the individual life-course, its effects are usually first detected in middle age or later (Kuh et al, 2004); this means that the projected population shift towards an ageing population will inevitably be

accompanied by a rise in the numbers of people suffering from a chronic disease.

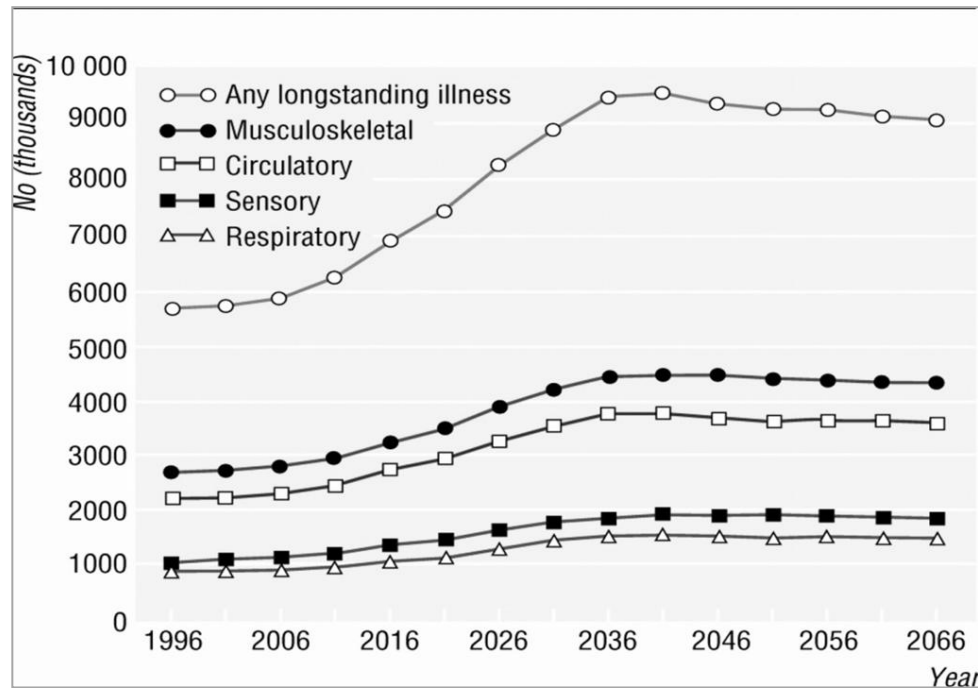


Figure 1.1 Projected number of people aged 65 or over with chronic illness in UK 1996-2066
Source: Khaw, 1999

Most projections suggest that the number of people over 60 in the UK will increase from 12 million, or 20% of the population in 2001, to around 18.6 million, or 30% of the population by 2031. Alongside this population age shift, population lifestyle changes manifested in changing diet and decreasing physical activity are also expected to add to the chronic disease burden.

3. THE CHRONIC DISEASE TRAJECTORY

In 1988, Strauss and Corbin developed a trajectory model of chronic disease, which

usefully described the different phases of disease that all chronic disease patients experience in some form over the course of their lives. The model has eight distinct phases of disease: diagnosis and disease onset; stable phases, where the patient maintains everyday activities; unstable periods, where symptoms cannot be kept under control; acute phases, requiring bed rest or hospitalisation; crisis phases, where emergency services are required; comeback phases that follow unstable or acute phases; decline and disability; and finally the dying phase.

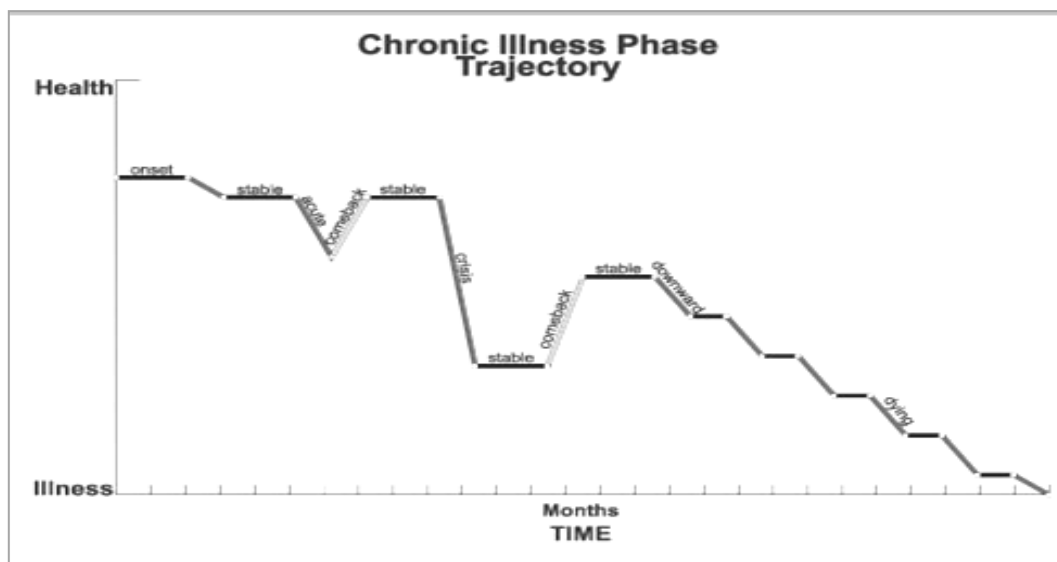


Figure 1.2 Corbin & Strauss' Chronic Illness Trajectory

http://www.unc.edu/courses/2010spring/nurs/595/960/chronic_illness-2003/ci_segment2.html

The model is useful, in that it shows why the management of conditions such as CHD is complex and demanding for both patient and doctor: there never a decisive 'cure' and there is no means of predicting the specific duration of any one phase in the disease - several phases may recur throughout a patient's lifetime.

4. CHD: CAUSES AND POPULATION PREVALENCE

Coronary heart disease (CHD) is one of the most prevalent chronic diseases. It is caused by a partial or complete blockage of arterial blood supply to the heart, often as a result of atherosclerosis, a build-up of fatty deposits in the artery. It can be experienced as angina - chest pain - due to inadequate blood flow to the heart muscle and can lead to a heart attack if left untreated. It is usually identified by a doctor using diagnostic tests and checks for symptoms such as breathlessness, chest pains or swelling of the legs and ankles. According to the Department of Health, CHD is the greatest cause of death and premature death in the UK: around 94,000 people die of heart disease annually. 2.6 million people in the UK have been diagnosed as having CHD, including around 110,000 people in the UK annually who have a heart attack and 2 million people who currently suffer the effects of angina (British Heart Foundation, 2010a). CHD also tends to occur in conjunction with other chronic diseases after the age of 65, and is particularly associated with hypertension and diabetes.

The last few decades have witnessed an overall drop in CHD mortality: death rates in the UK for CHD have fallen by 45% in the last decade in adults under 65, mostly due to the drop in smoking and improvements in medical treatment. However, demographic changes mean that an increase in the *prevalence* of CHD is expected as the population increases, and particularly as the population ages (Capewell et al, 2008).

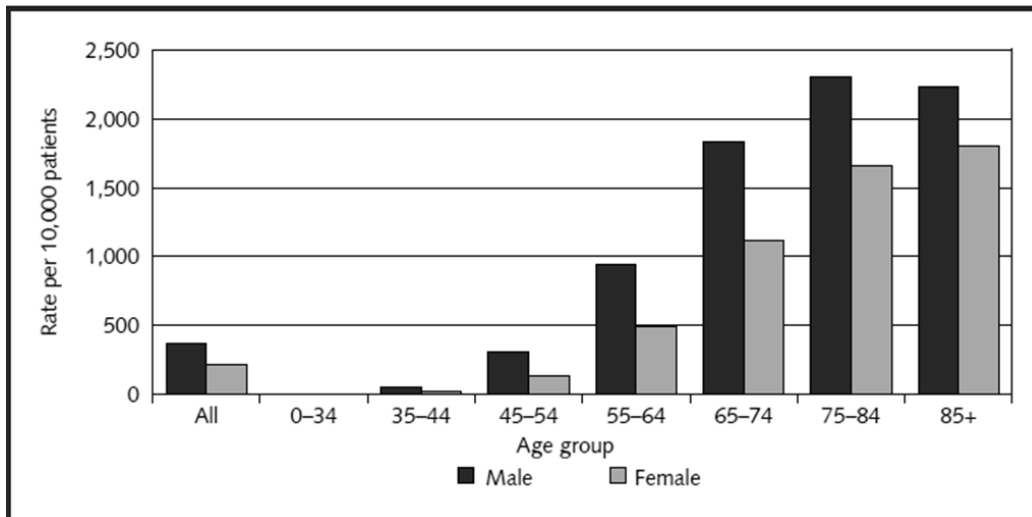


Figure 1.3 Prevalence of CHD per 10,000 patients in UK (Source ONS 2000)

Death rates have continued to fall in adults over 55, but are reported to be falling more slowly in younger adults and may even be increasing in the youngest age groups: for example in 2002, CHD mortality rates increased in men aged 35-44 for the first time in two decades. According to recent epidemiological studies by Vaccarino et al (2009), the number of heart attacks among middle-aged women in the US is actually increasing as it falls among men, even though survival rates are still better for women and men in the study. It remains to be seen whether the same trend will manifest itself among women in the UK. Research also shows that, even though overall heart disease mortality rates fell by 28% in the decade to 2007 in the US, the burden of heart disease is running so high that the number of heart procedures performed in US hospitals actually increased by 27% in the same period (Roger et al, 2010).

5. CHD AND THE PROBLEM OF LONG-TERM HEALTH MAINTENANCE

Perhaps the greatest contemporary challenge to improving chronic disease management is the need to find ways of improving the management of modifiable risk factors, in the form of the health behaviours that are so strongly associated with chronic diseases like CHD. Until the 1970's, coronary heart disease was an acute illness that often went undiagnosed until the individual concerned suffered and often died from a heart attack. Since then, research into diagnosis and secondary prevention of CHD has made a significant difference to morbidity and mortality rates: heart bypass surgery, stenting and medication such as statins, beta blockers, calcium channel blockers and ACE inhibitors have transformed heart disease into a largely chronic condition (Christensen et al, 2009). More recently, significant gains have been made in our understanding of the importance of managing modifiable lifestyle-related risk factors such as diet, exercise, alcohol intake, working hours and stress; yet, with the exception of smoking, such findings appear to have made little impact on many patients' long-term health behaviours.

There are also known CHD risk factors that are either not yet fully understood or are not easily amenable to change. So, for example, figures compiled by the Health Survey for England (HSE) show there are significant regional variations in CHD death rates, most notably in Northern Ireland, Scotland and Wales when compared to South-East England; and there are ethnic variations, especially among South Asian populations in the UK, who show a 50% higher premature CHD death rate compared to their white

counterparts (HSE 1998, 2006). Social inequalities are also a risk factor, as lower socio-economic position is associated with a threefold increase in premature mortality from CHD compared to higher socio-economic groups. Many primary risk factors are genetic, but lifestyle is known to have a significant influence on the likelihood of developing CHD where genetic factors are already present. So, for example, body shape is a known indicative risk factor: those who carry extra fat around their waistlines have a higher risk of developing CHD than their pear-shaped counterparts and this knowledge has increased our understanding of the importance of reducing central obesity in CHD patients as well as the population in general. We know that many CHD risk factors can at least be modified by lifestyle changes such as smoking cessation, reducing elevated cholesterol levels, reducing high blood pressure, managing diabetes, reducing obesity, reducing animal fat intake, increasing fruit and vegetable intake and increasing physical activity (HSE, 2008). Such measures have been shown to make a statistically significant difference to CHD morbidity and mortality rates: in the decade 1980-90, 58% of the decline in CHD mortality in the UK was attributable to reductions in major risk factors at a population level, especially smoking and to lesser degree, a reduction in population cholesterol and blood pressure. The remaining 42% of the drop in mortality was attributed to treatments to individuals, including secondary prevention such as improving health behaviours by modifying diet and increasing exercise, and the use of statins to lower blood pressure (Unal et al, 2004). Such changes are currently encouraged by the NHS, both as preventive measures and as secondary measures of controlling CHD once diagnosed, along with medication and surgery when necessary. However, both the literature and

the patient study that follows demonstrate that improving patient health behaviours remains both a challenge and a priority for doctors and patients alike.

6. CHD AND THE FUTURE OF CHRONIC DISEASE HEALTHCARE

The last decade has been devoted almost exclusively to the pursuit of greater efficiencies in the NHS, yet according to the British Heart Foundation, the UK still spends more of its healthcare budget on heart disease than any other EU country. CHD costs the UK economy an estimated £6.6 billion a year - £3.5 billion a year in direct health costs, and £3.1 billion a year in indirect costs such as absence from work due to death, illness or caring for others with CHD.

Despite the demographic shift towards chronic diseases as the primary causes of premature disability and death, the organisation and structure of the National Health Service is still heavily influenced by its original focus on acute and infectious disease. This is best exemplified by its continued practice of managing much secondary care provision in large hospitals with onsite treatment facilities and discrete clinical specialties. The effective treatment of a chronic disease requires a different approach to healthcare and there is growing recognition that the NHS needs to re-think how it should provide the kind of long-term care needed by the chronically ill, such as more emphasis on preventive measures, palliative treatments to reduce acute episodes, health monitoring and outpatient treatment from home.

In response to the expected escalation in chronic disease, healthcare planners are basing their more optimistic assumptions around health spend on the capacity of patients to take more responsibility for their health now and in the near future (Hunter, 2003; Wanless, 2002). The terms 'patient self-management' or 'patient self-care' are now used to describe this approach to disease management, summarised as 'collaboratively helping patients and their families acquire the skills and confidence to manage their chronic illness, providing self-management tools, and routinely assessing problems and accomplishments.' (Bodenheimer et al, 2002). Patient self-care is promoted in the health policy literature as a means of helping to manage the chronic disease burden and its associated costs more efficiently, with hopes pinned to a future vision of healthcare where both healthy lifestyles and rates of self-care will increase, in turn reducing pressure on GP and outpatient services and slowing the growth in NHS spend (Department of Health, 2006). However, it is also accepted that there is currently a paucity of data on which to base assumptions about the relative effectiveness of, and costs associated with, increasing patient responsibility for managing their own chronic disease (Wanless, 2004).

Derek Wanless' reports to the Treasury in 2002 and 2004 tried to anticipate the future challenges of managing the growing financial burden of healthcare in an ageing society. The reports estimated that £30bn could be saved through individuals taking greater responsibility for their health, with major improvements expected in healthy life expectancy if rates of smoking are reduced, exercise increased and a healthier diet adopted in the population as a whole. Wanless also realised that any such changes in

population health would necessitate a greater degree of population engagement with healthcare than heretofore. Since then, the Department of Health has been actively encouraging primary care doctors to increase levels of patient self-care among those with a chronic condition, as part of the NHS Improvement Plan introduced in 2003.

The NHS Plan set out a 3-point system of interventions among people with chronic conditions: intensive co-ordinated case management between GPs and primary care teams for patients with multiple complex needs; structured chronic disease management mostly at primary care level for patients with less complex cases; and GP encouragement of self-care as an essential element of care for all patients with long-term conditions, particularly those not in need of intensive disease management (DoH, 2003a).

Lord Darzi's 2008 report on the future of the NHS continued to stress the need for a patient-focused NHS, and the next few years saw a flurry of activity around the themes of patient and public involvement. The current administration seems set to continue the trend: upon gaining office, Health Secretary Andrew Lansley's 2010 White Paper on Health promised more patient choice and control, coining the phrase 'no decisions about me, without me'. However, more needs to be done to investigate the organisational implications of closer patient involvement in self-care: for example, its impact upon the doctor-patient relationship, its effect on patient knowledge-seeking, the kind of NHS configuration and care pathways required to support self-care, the different values and priorities that may be placed on healthcare if patients are given

more influence.

7. STUDY RELEVANCE

If patients are to play a greater part in their own healthcare, it is safe to suggest that managing the knowledge flow between patients and health practitioners needs to assume an enhanced role in NHS organisation and practice.

This study was prompted by the desire to understand more about how chronic disease patients, specifically patients with CHD, track down the knowledge and information about their condition they need, and to identify some of the knowledge management implications of a more expanded role for the patient in their own long-term healthcare. The advent of mass social networking and access to the internet also begs the question whether such patients may themselves generate knowledge in new ways about their condition that could be of use more broadly to other patients and to the organisations that serve them.

8. THESIS STRUCTURE

This study is set out as follows: chapter 2 describes key developments in knowledge management theory and identifies theoretical and practical issues that relate specifically to NHS healthcare and to chronic disease patients.

Chapter 3 reviews the existing literature in the three areas that relate directly to this study: knowledge-seeking among CHD patients and chronic disease patients generally;

the effectiveness of existing knowledge management interventions aimed at such patients; and the small amount of literature that discusses knowledge creation among chronic disease patients, which is a new area of academic and practical interest.

Chapter 4 sets out the methods used in this study, focussing on a brief explanation of the grounded theory method and theoretical considerations relevant to this study, as well as the study design, related ethical matters, data collection and analysis and the patient study schedule.

Chapter 5 provides a profile of the patients from the Camden Primary Care Trust (PCT) area included in the study.

Chapter 6 sets out the results that relate to the first research question: 'What sources do patients use when seeking knowledge about their condition, and what are their reasons for doing so?'.

Chapter 7 sets out the results that relate to the second research question: 'Do patients, in the course of managing their CHD, generate knowledge about the condition and its treatment?'.

Chapter 8 reports the results of a questionnaire sent to GPs in the Camden PCT area, as the results relate to the two research questions identified above.

Chapter 9 interprets the study findings in light of the existing literature and also considers the study's limitations. The findings associated with the two research questions are examined and discussed in turn, as are their broader implications. Suggestions for future work are made. The chapter concludes by summarising the study findings and the directions for future study.

Any existing literature mentioned throughout this work is can be found in the reference section at the back, as can all appendices.

CHAPTER 2 | KNOWLEDGE MANAGEMENT: INTELLECTUAL FRAMEWORK AND ISSUES SPECIFIC TO THE NHS

1. INTRODUCTION

This chapter looks at knowledge management (KM) and its key theoretical developments. This is not intended to be an exhaustive review of knowledge management theory and practice, but rather a digest to help contextualise some of the issues relating to NHS healthcare and patient knowledge in the study. The latter part of the chapter examines knowledge management issues specific to the NHS and to patients in the existing literature. The chapter concludes with a summary of the key aspects of knowledge management theory that are brought to bear in the patient study.

2. DEFINITIONS

2.1 Knowledge management

Knowledge management is an umbrella term for a range of theories and methods that relate to the conscious identification, distribution and/or generation of organisational knowledge in ways that seek to endow that organisation with competitive advantages. As a discipline, it has its philosophical roots in epistemology and emerged as a discreet academic subject in the 1990's. It is an intellectual response to the problem of knowledge as an organisational asset and implicitly acknowledges that the existence of

valuable commercial knowledge within or without an organisation does not automatically mean that the organisation can access and benefit from it.

KM theory and practice tends to divide into three main tendencies: firstly, there is the technological, IT-driven approach, which tends to concentrate its efforts on knowledge databases and repositories, or more recently, other knowledge communication tools such as neural networks developed by Malhotra (2001) or Young (1999). The second tendency concentrates on organisational process and design, focussing on the organisational management of knowledge transfer, codification and knowledge generation among employees, as seen in the work of Davenport and Prusak (2000) and Firestone and McElroy (2003). The third tendency is more ecological, concentrating on systems of human interaction, communities of practice, social network analysis and other relational aspects of knowledge creation, as exemplified by Wenger et al (2002) and Thomas et al (2001).

2.2 Knowledge

The definition of what constitutes knowledge is a matter of serious philosophical debate, so it should not be surprising that there is a lack of theoretical clarity in KM circles. With some honourable exceptions, the KM literature rarely examines the mediations between human activity, individual knowledge and its organisational expression. Debates still revolve around whether knowledge is a thing in itself to be captured, shared and managed through process, as asserted by Firestone (2008) or

itself a process, described by Nonaka and Takeuchi (1992) as information flow transformed by the activity of the human mind, a classical definition of knowledge that harks back to Aristotle. There is also disagreement around the distinction to be made between knowledge and information, as knowledge management often struggles to distinguish itself from the narrower confines and smaller ambitions of information management. This author sees the theoretical distinctions between knowledge and information as, at best, contextual: a useful distinction between information and knowledge is provided by Davenport and Prusak (2000), who understand knowledge to be the product of information processed through the agency of the human mind and thereby adapted and contextualised to meet the requirements of a given problem or situation. Davenport and Prusak developed the idea of how knowledge thus understood might inform organisational activity at the level of both people, as knowledge 'in the the minds of the knowers' and processes, as knowledge 'embedded in documents...organisational routines, processes, practices and norms.'

KM developed beyond its initial positivist approach as it became evident that knowledge could not be as easily commoditised as other organisational assets (Blackler *et al*, 1998). Later KM thinkers showed evidence of a more social constructivist view of knowledge, where knowledge exists, not as an entity outside the sphere of social relations, but as an activity, realised through the process of human interaction in a specific social and historical context. Tsoukos and Vladimirou (2001) describe the dialectic of knowledge both as a thing and as a process; knowledge management is defined as the act of consciously facilitating and attempting to improve upon an

ongoing organisational process that happens in some unconscious form even without being identified: 'the dynamic process of turning an unreflexive practice into a reflective one by elucidating the rules guiding the activities of the practice, by helping give a particular shape to collective understandings, and by facilitating the emergence of heuristic knowledge'. Tsoukos et al's conception of knowledge management acknowledges the tension that necessarily exists between the individual as knowledge provider and the organisational drive to manage that knowledge.

2.3 Tacit knowledge

KM theories of tacit and explicit knowledge are based on scientist-philosopher Michael Polanyi's theorisation of the hidden workings behind the individual creative act. In reaction to the post-war positivist view of science as objective and value-free, Polanyi argued that scientific discoveries resulted from the creative tension between the rational interrogation of a subject and other, more tacit forms of knowing. In *The Tacit Dimension* (1964) and *Personal Knowledge: Towards a Post Critical Philosophy* (1966), Polanyi further defined hidden, tacit knowledge as localised, personal knowledge grounded in experience and in learned practices and traditions. Thus defined, tacit knowledge contained so much embedded learning that it was virtually impossible to reproduce in a codified form and was best inferred through demonstration and imitation. For Polanyi, tacit knowledge explained how practice and tradition could result in an individual knowing more than he or she could actually articulate; it also explained how knowledge that was articulated was often at least partly composed of

tacit knowledge that was never openly expressed.

The value of this (originally Aristotelian) distinction between knowing how to do something, or 'know how', as opposed to explicitly knowing about it, or 'know what', was rediscovered by thinkers and academics responding to new challenges thrown up by computerisation and the ensuing disciplines of information storage and systems development. Two new problems emerged from this information boom: the problem of locating desired knowledge in a timely way from the flood of information readily available, and the problem of knowledge or expertise that was not readily reproducible in a systematic and electronically storable fashion. Explicit knowledge, that is, any knowledge that could be codified in writing and universally understood in the form of facts, policies, rules or relationships is what organisational systems could manage best (Wyatt, 2000). Tacit knowledge could not be so easily abstracted, if at all; it is formed in the individual mind and expressed in the form of individual skills and expertise in ways that are impossible to codify, but can at best be learned through demonstration and emulation (Nonaka et al, 1994; Tsoukas, 2003). It could exist in two distinct forms: as knowledge embodied in people and their social networks and as knowledge embedded in the processes and products that people created (Horvath, 2000).

Systems engineering was unable to capture the more embedded, tacit forms of organisational knowledge, and it became clear that the totality of activity around knowledge generation and transfer could not be satisfactorily computerised, as important aspects of knowledge transfer and knowledge generation were found to be

a largely human and social rather than a mechanical process (Balconi, 2002).

3. THE THEORISATION OF ORGANISATIONAL KNOWLEDGE

3.1 The knowledge worker

The experience of Western industrial decline and the rise of the service and financial sectors gave rise to the idea of the knowledge society, first articulated by writer and management consultant Peter Drucker in 1993 to explain what type of economy might replace that built on an outdated Western manufacturing base. Rules that governed success in an industrial economy were rendered obsolete in a globalising economy where knowledge, in the form of know-how and expertise, was at least as critical as other, more tangible economic resources. Company downsizing drew attention to the fact that a company's intellectual assets were often tied up in a few key individuals who had just left the building. The capture and distribution of knowledge and the elimination of organisational and psychological barriers to information sharing in organisations became a business imperative. Knowledge workers – identified as those who used their intellectual powers rather than their manual labour – were the essential ingredient in this new economic outlook. The emergence of the service sector along with accelerated technological change gave added emphasis to the idea of value produced, not through hard assets, but through the less tangible human agency of the knowledge worker. The rapid supply of knowledge and information was understood to be central to organisational and economic success in this new post-industrial, innovation-driven culture. Chief Knowledge Officers in companies such as

Scandia and CIBC, charged with maximising their companies' intangible assets, became interested in the theoretical aspects of their practice: as a result, knowledge management was taken up by university academics as a new area of business research in the early 1990's.

3.2 Tacit knowledge as the key to organisational innovation

Business philosophies from the Japanese manufacturing industry influenced organisational thinking in the West in the 1970's and 80's: Japanese manufacturing practices such as flatter, less hierarchical social and organisational work structures attracted attention, as they appeared to facilitate knowledge exchange and increase trust among employees. Ideas like the 'learning organisation' emphasised total employee involvement in identifying and solving organisational problems (Brown et al, 2000; Wasko et al, 2000; Senge, 1992). In 1995, Ikujiro Nonaka and Hirotaka Takeuchi in Japan's Hitosubashi University published a theoretical model that addressed a key KM question: how can tacit knowledge, in the form of embodied, individual knowledge and expertise, be extracted and converted into explicit organisational knowledge that might contribute significant commercial advantage?

Their SECI model of knowledge conversion¹ theorised that tacit knowledge could be transferred to other individuals through a process of Socialisation, or close social interaction; that tacit knowledge thus shared could then be rendered explicit through

¹ SECI: socialisation, externalisation, combination and internalisation

a process of Externalisation, that is, through embedding the shared tacit knowledge in concepts that were communicable (figure 2.1).

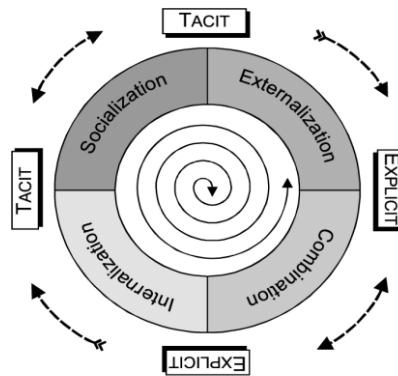


Figure 2.1 Nonaka & Takeuchi's model of knowledge creation

Through Combination, or combining elements of externalised knowledge in action, this explicit knowledge could then undergo Internalisation, that is, such knowledge could be internalised as a new factor in each participator's knowledge base: though his or her subsequent organisational contributions, the individual would thus help to maintain the spiral of organisational knowledge sharing and knowledge generation.

The development of a popular home bread making machine by Japanese company Matsushita in 1985 was used by Nonaka to exemplify how the transfer of tacit knowledge could be used to innovate. In this case, innovation occurred through the transfer and conversion of tacit knowledge from the hands and mind of the best baker in the Osaka International Hotel, into explicit usable knowledge through close observation of the baker by a member of the software development team (Nonaka et al, 1995). The observed learning was then externalised to 11 other selected members

of the Matsushita workforce, who combined the new knowledge with other areas of expertise to create an effective new product for market. Such knowledge could then be internalised by the organisation as a whole and form a new part of its knowledge base, with the capability to act as a catalyst in other areas of product development and production.

This model of knowledge creation has proved popular among KM practitioners and management theorists. Nonaka's model implies that there is innovating potential inherent in every organisation, if one can but find the processes that facilitate the conversion of embodied knowledge and expertise into explicit organisational knowledge. This model of knowledge generation focuses on the utilisation of *existing* knowledge, which some critics view as an overemphasis on the role of knowledge conversion in knowledge creation (Firestone, 2001). Others regard the very notion of knowledge conversion as flawed, in that tacit knowledge, by its very nature, cannot be made explicit and cannot be 'converted', but only demonstrated in practice (Tsoukas, 2003). However, the value of the Nonaka and Takeuchi model of knowledge creation is twofold: it identifies the centrality of human agency in knowledge creation, and it understands that a number of mediations may be required to translate individual human knowledge, whether tacit or explicit, into organisational value.

3.3 Communities of practice

From around 2000 onwards, the development of web 2.0 applications and user-

generated content in the form of web-based communities, social networking sites, wikis and blogs, added flesh to the idea that knowledge embedded in the individual could be of significant commercial importance if ways were found to liberate it. A more ecological approach to KM was developed around the ideas of situated learning (Hildreth et al, 2004) and Lave and Wenger's concept of communities of practice, a phrase coined by Etienne Wenger to describe what he called 'groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise by interacting on an ongoing basis' (Lave et al, 1991). It was also apparent that the IT-led approach to knowledge management, for example using databases to capture knowledge and make it available to a wider network of people, often did not work, as there was often little evidence of there being much human interest in using them (Stapleton et al, 2005; Newman, 2002; Wenger et al, 2002). Communities of practice were seen as an important means of being able to capture and share both codified knowledge, such as best practice, *and* the tacit knowledge tied up in human expertise; the interaction within such self-identified professional groups was understood to facilitate learning generally and knowledge conversion in particular. (Wenger et al, 2002; Duguid, 2005).

3.4 First and second generation KM

It is common in the literature to see references to first and second generation KM. First generation KM is often described as 'single loop learning', as it focuses on KM strategy that modifies organisational practice in order to mesh together policies and

information systems designed to collect and codify existing knowledge, such as decision support tools and data mining. Second generation KM characterises the contribution of many of the key KM thinkers from the mid-1990's onwards, and is also described as 'double loop learning', in that it describes KM processes that seek to improve an organisation's capacity for knowledge *creation*, in order to be more responsive to changing economic and social circumstances internal or external to that organisation (Firestone and McElroy, 2003; von Krogh and Roos, 1995). In stark contrast to an organisational tendency towards downsizing and optimisation of existing products and processes in response to economic recession, many second generation KM thinkers stressed the importance of innovation as a key ingredient in knowledge management strategy. Knowledge management thinkers such as David Snowden (2002) and Karl Eric Sveiby (1997) took greater account of the role of human agency and cognitive processes in value creation, as the significance of individual and collective motivation in relation to organisational knowledge became apparent. Victor Newman (1997) emphasised the idea of knowledge as a creative process rather than as an object in itself and argued for the importance of maintaining a dynamic interaction between those predisposed towards creative, implementing or stabilizing impulses within an organisation seeking competitive advantage.

4. THE LIMITATIONS OF KNOWLEDGE MANAGEMENT THEORY

KM advocates are keen to promote the organisational value of knowledge management and assert its centrality to sustaining an organisation's intellectual capital (Marr et al, 2001). Many famous multinational corporations such as Shell, Toyota, the

World Bank and Ernst and Young have engaged with knowledge management ideas in an attempt to manage best practice and company learning and innovation at an international level. However, the academic discussion around KM still exists primarily at the level of anecdote and individual case analysis. It is hard to validate assertions of organisational and commercial value in the absence of any serious attempt at developing metrics that can provide objective evaluations of the range of interventions and organisational structures associated with knowledge management methodology – or, in the case of a more ecological approach, show the linkages between organisational outcomes and the social mechanisms at work (Firestone, 2008; Lesser et al, 2001). As an academic discipline, KM is disadvantaged by the fact that there has still been no serious attempt to measure its corporate contribution or value: at the time of writing this study, there are still no systematic reviews that assess the value (or the outcomes) of KM practice in the public or private sector.

5. KNOWLEDGE MANAGEMENT-RELATED ISSUES SPECIFIC TO THE NHS

In the UK, knowledge management tends to be the preserve of the private sector and until recently, knowledge management here has been largely associated with the development of IT solutions for handling issues of knowledge storage and sharing (Bate et al 2002). More recently, some of the larger private and public sector organisations, ranging from British Telecom and Anderson Consulting, to BAe Systems and the Home Office, have started to experiment with the management of intellectual

capital, seeking new ways to learn from their customers and workforce. At the same time, the NHS has arguably been moving in the methodologically opposite direction.

The last few decades has seen the NHS promote the values of evidence-based medicine, clinical targets and other 'top down' methods of determining clinical practice and procedure. Even so, the NHS has not remained untouched by the interest in innovation associated with public service modernisation, inspired by Peter Senge's influential theory of 'the learning organisation' – one that can adapt to changing circumstances, and train its employees to contribute to its development. In 2000, the Labour Government announced the introduction of the NHS Plan, designed to modernise the NHS workforce and reorganise staff according to their skills rather than traditional professions-based demarcations. The NHS Executive declared that they wanted to encourage innovation across health organisations and professions, in an 'open and participative culture in which knowledge sharing flourishes'. However, there were three major barriers to this style of knowledge management and innovation to contend with: the technological problem of information overload and targeted knowledge distribution; the structural problems created by bureaucratic departmentalised working methods; and the cultural and professional boundary marking that impeded knowledge sharing and innovation.

The first conscious KM strategy for the NHS was developed by the Department of Health in 1999. It consisted of promoting to local NHS organisations the value of encouraging the culture of knowledge sharing in NHS bodies and making knowledge

bases available to those engaged in healthcare who might benefit. It also entailed improving the relevant technology skills of those who might then use them (Fawcett, 2008). These first stage knowledge management interventions tended to focus on IT-based information systems such as best practice databases and information and document repositories. More recently, social mechanisms, such as communities of interest and practice, with the emphasis on knowledge sharing and evaluation have been encouraged and have some NHS presence: however, critics argue that they can make little impact on knowledge sharing in such an hierarchical organisation (Ferlie et al, 2003).

Knowledge management interventions aimed at patients have been slower to develop: ideas around the interactive sharing of clinical knowledge with patients is still in its infancy.

5.1 Technical barriers to knowledge management

It is perhaps unsurprising that knowledge management in NHS healthcare is most in evidence in the areas of IT and libraries: the management, distribution and integration of knowledge, data and information around a widely dispersed and heterogeneous workforce remain a significant organisational challenge. The NHS 'information paradox' is that medical staff can be so overwhelmed with information that they cannot find what they need in a timely way. This paradox helps to explain why it is that, despite the generation of so much information-rich data, the NHS seems to have

problems using it in ways that improve decision making or service delivery (Hibble et al, 1998). So for example, in 2000, it was estimated that each UK physician spent on average 25% of his or her time managing information (Dwivedi et al, 2005); two million new clinical specifics were available to them and each received about 15kg in weight of clinical guidance literature every year (Wyatt, 2000). In 2002, the National Library of Medicine's Medline database of published literature on health-related sciences contained 11.7 million citations, with about 400,000 new entries added per year: it is calculated that, even if 1% of the new literature added every year were relevant to a physician, it would take him or her 5 years, reading two articles per day, to catch up with one year's relevant publications (Masys, 2002).

The new discipline of Medical Informatics has emerged in response: data mining tools, the IT systems used for searching and analysing large amounts of data are an attempt at managing knowledge volume. KM tools, ranging from the specialist and non-specialist e-libraries that make up the National Library for Health, to patient decision support systems used in some hospital departments, are increasingly available, although a systematic evaluation of their effectiveness remains outstanding.

In a 2007 review of the literature on KM in the NHS, Nicolini et al observe that many NHS-based KM systems have often been developed with insufficient involvement and care for the end user and are often under-utilised as a result. In any case, computer-based systems are also limited in what they can achieve: they cannot manage the tacit,

embodied knowledge that plays a significant role in the transfer and application of medical knowledge (Davenport et al, 2000).

5.2 Structural barriers

The second KM-related problem in the NHS concerns the nature of the work as currently organised. NHS healthcare is at once both a highly collaborative process, involving a wide range of health professionals and administrators *and* a highly centralised, bureaucratic and compartmentalised model of service delivery. Medical staff work primarily in sharply delineated professional networks, defined by their clinical specialty and specific expertise: multi-disciplinary teams are still in their infancy and often end up replicating the rigid NHS hierarchies in microcosm (Ferlie et al, 2003). One patient's treatment often involves moving between a number of different healthcare professionals with highly specific job functions: as a result, the data that helps co-ordinate and record each patient's treatment is usually held in a range of locations, is administered by a range of different people using different administrative methods and is stored in any number of formats. This in itself raises major challenges for ensuring the timely and accurate flow of knowledge and information between those involved in the treatment of a single patient, long before any additional consideration is given to engaging the patient in what is often a convoluted care process.

5.3 Cultural Barriers

Of all the public sector organisations, the NHS is considered to be among the most hamstrung by cultural barriers that impede effective knowledge sharing and transfer (Currie et al, 2007). Quite apart from the technical and administrative obstacles, knowledge sharing, even between medical professionals, often proves elusive due to the many professional boundaries inherent in the healthcare professions (Ferlie et al, 2003). This does not bode well for any proposed increase in patient autonomy: the reluctance amongst health professions to relinquish the power and responsibility required to empower the patient has been identified as a significant obstacle to patient involvement in clinical matters (Bate et al, 2006).

The push from the NHS centre for clinician adherence to evidence-based medicine suffers from having little bearing on how medical knowledge and learning is transmitted *in practice*. Studies have shown that employees in general spend a third of their time looking for information, and are five times more likely to turn to a co-worker than an explicit source of information such as a book or database (Davenport et al, 2000). This finding was echoed in research into clinician knowledge-seeking, which also found that knowledge exchange worked best under conditions of operational proximity; knowledge appeared to circulate most easily within closely knit communities of practice, where tacit, embodied ways of knowing could be imitated and internalised (Amin et al, 2008). In sharp contrast to evidence-based medical practice, it is reported that clinicians rarely operate on the basis of explicit research

evidence, preferring the more tacit and collectively reinforced knowledge built up from their more proximate interactions with work colleagues, pharmaceutical reps, patients and opinion formers (Gabbay et al, 2004).

Online NHS communities of practice began to spring up from 2007 onwards, with initiatives such as CHAIN (the Contact, Help, Advice and Information Network for people working in health and social care) and eSpace, an online collaboration tool to enable NHS employees to share knowledge about new technology.² However, such communities may involve less democratisation of knowledge than anticipated: evidence suggests that professional communities of practice in an hierarchical organisation like the NHS encourage learning *inside* the professional grouping, but that such communities also reinforce the hoarding of knowledge in professional silos, and thus fail to contribute to the distribution and generation of knowledge more broadly among the range of professionals involved in patient care (Ferlie et al, 2005). It is reported that even where advances in technology and the use of multi-disciplinary teams have threatened to erode the hierarchies and professional barriers to knowledge transfer, progress only takes place where there is a high degree of consent from the traditional knowledge gatekeepers, such as senior consultants (Martin et al, 2009).

² Interestingly, Healthspace, the NHS personal health organiser aimed at patients, devised to be their eventual gateway to online NHS care records, was quietly shelved before the parliamentary elections in 2010 by the Department of Health pending re-evaluation of its business case.

Effective knowledge management in the NHS would mean that organisational knowledge and innovation, generated from evidence and creative best practice, could be gathered and diffused quickly *across* professional and cultural boundaries, and made available to the entire health economy. The NHS at present exemplifies why knowledge cannot circulate freely in an organisation simply because the technology to support its circulation is available (Feldman et al, 1981). It also explains why patient groups continue to fight so hard for meaningful involvement in matters relating to their health and medical welfare. It remains to be seen whether the political exigencies of greater patient self-care will help distribute medical power and knowledge in ways that have a positive effect on health outcomes.

6. THE RISE OF THE PATIENT AS AGENT

A recent review of knowledge management in the NHS noted that most of the KM-related work to date has focused on practitioners rather than patients (Nicolini et al, 2007). Meanwhile, it has also been noted that the independent pursuit of medical knowledge and information by patients may be altering the doctor-patient relationship in ways that are likely to increase, rather than improve, communication problems (Davenport et al, 1997). A 1999 survey by the pharmaceutical industry (ABPI) reported that only 21% of doctors were in favour of the government's proposals on the expert patient; 58% predicted an increase in the workload of general practitioners; 42% believed it would increase NHS costs; and only 12% thought it would improve relationships between doctors and patients. In 2003, a MORI survey of health

professionals found that 63% of doctors thought that, in the long run, better informed patients would require more of their time.

‘The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed.’ (Shaw & Baker, 2004)

Trends in CHD patient care, discussed more fully in chapter 3, indicate that medical knowledge, as well as medical responsibility, will need to be shared more fully with patients, both as individuals and as communities of interest if patients are to be encouraged to engage with their healthcare.

It is against this backdrop that the role of patient knowledge in chronic disease management acquires its significance: increased CHD patient self-care requires that healthcare professionals have a better understanding of how patients manage their knowledge, how that knowledge moves between patients and their knowledge sources – and also why it sometimes doesn’t. Greater comprehension of how patients seek knowledge about their medical conditions is required, not just for reasons of health economics, but also because it affects health outcomes: methods of delivering healthcare that fail to recognise the role patient knowledge plays with respect to their disease can result in the wrong treatment decisions (Segal, 1998). Equally, if human activity, experience and their interplay with existing ideas creates the conditions for

generating new knowledge, it is to be expected that at least some patients generate some kind of knowledge in the course of interacting with their chronic condition and the NHS system of healthcare for years if not decades of their lives. At present, little is known about patient knowledge generation.

6.1 CHD patients: health consumers and lay practitioners

Knowledge management theorists have demonstrated how individuals *within* organisations can benefit from organisational learning, and can, under the right conditions, also generate knowledge and innovation in the form of new learning resulting from their organisational involvement. However, chronic disease patients are not employees: they are not healthcare professionals, but nor are they simple healthcare consumers.

Much has been written about the extent to which patients can be described as consumers. The very concept of patient-consumers has changed over time, from being patients-rights led in the 1960's, to being more approved and state-sponsored from the 1980's onwards, and often associated by successive government administrations with the promotion of NHS reforms (Mold, 2010). The depiction of patients as healthcare consumers fails to recognise the additional status, especially of chronic disease patients, as long-term lay practitioners of self-healthcare. Indeed, it has been argued for over a decade that, alongside health professionals, chronic disease patients become partners in their disease management, as a patient's own knowledge base,

developed over the course of the disease, makes a significant contribution to the patient's ability to manage that disease (Holmen et al, 2000; Wilson, 1999).

Chronic disease patients such as those with CHD therefore have features common to communities of practice: they share a common interest in their chronic disease, about which they may exchange ideas with other interested parties, but they can also put some ideas of common interest into practice directly in their capacity as self-carers.

7. SUMMARY: THE APPLICATION OF KM THEORY IN THIS STUDY

At a theoretical level, this study benefits from knowledge management theory and analysis in several ways. KM theory elaborates how knowledge can be seen as an object in itself or an activity - or both. It identifies the different ways in which learnign may be acquired – tactily, explicitly, individually, organisationally. It makes clear why knowledge distribution and creation in an organisation are both vital to the creation of added value and organisational survival in the marketplace, as well as fraught with contextual challenges. Specifically, it helps to identify the three areas of knowledge that may affect patient knowledge seeking and knowledge generation – the technological, organisational and relational aspects of knowledge seeking and knowledge creation, as elaborated by some of KM's key thinkers mentioned in the previous chapter.

The examination of knowledge management in healthcare by Martin et al (2009), Ferlie et al (2003) and Bate et al (2006) helps to explain the wider organisational and ecological context within which knowledge is managed in the contemporary NHS. They identify many of the existing barriers that impede the flow and generation of knowledge and explain why patient knowledge-seeking is often viewed with ambivalence by NHS practitioners: the literature thus far has less to say about how these barriers can be overcome. The idea that patients might also *generate* knowledge relating to their medical condition is not a feature of medical research and development, which tends to be segregated from medical practice (Nicolini et al, 2007).

KM theory concerning the possible role of tacit individual knowledge in the distribution and generation of organisational knowledge alerts the author to the possible role tacit knowledge may play in patient knowledge generation. The author is also sensitised to the fact that knowledge conversion theory might help to identify the mediations between individual patient knowledge and its conversion into knowledge of organisational value.

3 | REVIEW OF THE LITERATURE

1. INTRODUCTION

This chapter reviews the existing literature that is of relevance to the research questions. It falls into three parts: the first section reviews what is known about knowledge and knowledge-seeking among CHD patients and chronic disease patients generally; the second section reviews what is known about the effectiveness of existing knowledge management interventions aimed at CHD patients and chronic disease patients generally; the final section examines what little is known and discussed in the literature regarding knowledge creation among CHD patients and chronic disease patients generally.

The literature review examines not only studies that focus specifically on CHD patients, but also includes work based more broadly on chronic disease patients, where the subject matter relates to areas of interest in this study. There is a substantial volume of published papers relating to patient knowledge and chronic disease management on the subject of health interventions aimed at assisting patients to manage their conditions. In terms of CHD patients, there is a rich literature, especially in relation to cardiac rehabilitation and its various components. An examination of patient knowledge-seeking is rarely the primary objective of the aforementioned types of study, as the majority are seeking to evaluate the efficacy or effectiveness of a

particular intervention: however, some useful study evidence relevant to patient knowledge-seeking can be glimpsed in the findings.

The key similarities, differences and gaps in the literature with respect to the current study are summarised at the end of the chapter.

2. PATIENT KNOWLEDGE-SEEKING

NHS patient self-care policy initiatives have coincided with the emergence of a new type of patient – a more informed, more knowledgeable and more demanding consumer of healthcare, often with computer access to independent sources of health expertise and information (Berg, 2005). Increased patient self-care presupposes a very different therapeutic relationship between doctor and patient: there is an expectation embedded in most policy documents over the last decade that chronic disease patients in particular will play a more active role in managing their own health in the near future, as partners rather than as passive recipients of medical wisdom (Wanless, 2002). How this should inform the traditional therapeutic doctor-patient relationship is less clear.

2.1 Barriers to patient clinical involvement

Research evidence supports the view that patient clinical involvement is the most effective known method of both improving health outcomes, drug compliance and increasing patient satisfaction (Coulter et al, 2008; Haynes et al, 2002; Stewart et al,

1999), but identifies the traditional social relationship between doctor and patient as a key stumbling block (Broom, 2005). A international study by the Picker Institute Europe compared the UK doctor-patient relationship with its equivalents in Australia, Canada, New Zealand, Germany and the USA (Coulter, 2006). Evidence showed that UK patients received less support from health professionals for engagement with their healthcare than patients in the other countries studied, specifically in the areas of preventive healthcare, patient self-care and patient involvement in treatment decisions. The report went on to suggest that UK health policy had promoted patient involvement in planning and service development, rather than concentrating on *improving communication* between individual patient and doctors, even though the latter was of more concern to patients:

‘Despite many efforts to promote patient and public involvement, there has been a failure to tackle the most important issue, namely the quality of interactions between patients and clinicians. Patients’ role as active partners in their healthcare is insufficiently recognised and supported by health professionals. What is needed is a major change in the way professionals work with patients in the UK.’ (Coulter, 2006).

Sources of information available to the public have proliferated over the last decade, due primarily to the widespread access to web-based information, even if the nature of the information available varies widely in terms of accuracy and complexity. A number of studies recommend that health professionals need to play a mediating role between sources of information and the patient, thus aiding the patient decision-making process (Lamond et al, 2000; Detmer et al, 2003): however, research indicates

that patients are not obtaining support from health professionals in making sense of the health information available and that they fail to receive essential information as a result (Coulter, 1999; Smith, 2000).

A detailed study of 1,000 consultations in US primary and secondary care reported that only 9% of the decisions made by patients were considered by the study authors to be adequately informed (Braddock et al, 1999). The average consultation studied lasted 16.5 minutes, which is considerably longer than a GP consultation in the UK: according to the BMA, UK consultations average around 8-10 minutes. British GPs tend to overestimate the extent to which they discuss information such as medication risks and treatment plans with their patients (Makoul et al, 1995). A systematic review of 28 studies of health professionals' perceptions of their knowledge-sharing behaviour with their patients showed that time constraints, patient characteristics and the clinical situation itself were the three reasons most often cited by health professionals for failing to share information (Gravel et al, 2006).

When it comes to patient expectations of doctors, successive studies show that effective knowledge transfer between medic and patient is positively related to both patient and doctor satisfaction, as well as patient compliance and medical outcomes, whether measured physiologically, behaviourally (in terms of functional status) or more subjectively, in terms of overall health status (Ong et al, 1995; Stewart, 1995; Epstein et al, 1993; Kaplan et al, 1989). In general, patients tend to want doctors to

provide more information than they do (Pinder, 1990; Beisecker et al, 1990). MORI polls from 2001 onwards reported that younger and more middle-class patients were able to seek information from a greater variety of sources, most notably the internet, before making major decisions, which both accompanied and perhaps helped to explain some of the public erosion of trust in doctors.

2.2 Patient knowledge sources

Studies that specifically address knowledge-seeking among CHD patients report two main topics of interest: firstly, such patients seek practical and honest information about their condition; and secondly, they seek advice on how to modify lifestyle risk factors (Campbell et al, 1994; Duryee, 1992). Only one study noted in passing that many patients appear to give more weight to health information provided by family and friends than by health professionals (Murray et al, 1989), a comment which finds some resonance in the patient study that follows.

Research indicates that patients often feel they are given insufficient information about lifestyle modification (Gambling, 2003; Thomas, 1994; Webster et al, 2002) and find that they have insufficient knowledge to be able to make lifestyle changes (Bergman et al, 2001; Condon et al, 2006; Karner et al, 2002). So, for example, patients asked to modify their eating habits were reported to know that they needed to reduce their fat intake but were often unsure about exactly what they *should* be eating (Bergman et al, 2001; Crane, 2001; Gambling, 2003). Inadequate provision of

appropriate information was reported to be a particular problem for certain groups of patients, such as people from lower socio-economic groups and those from ethnic minority backgrounds (King et al, 2006; King, 2002; Webster et al, 2002). However, a number of studies report findings that contradict the idea of patient knowledge as a primary stumbling block to patient efforts at lifestyle modification. These studies conclude that the population as whole, from the more to the less educated, all tend to have a good knowledge and understanding of the modifiable risk factors for CHD, even if knowledge of these factors does not necessarily lead to action to minimise their effects (Davison et al, 1991; Gabhainn et al, 1999; Narevic et al, 2003; Angus et al, 2005). Apparent contradictions in reported findings are of interest, as the role of patient knowledge in managing health behaviours is investigated in some detail in the study that follows.

On the broader topic of patient self-care, a national phone survey by the Picker Institute in 2005 asked patients whether they felt they had the knowledge necessary to self-manage their illnesses: the elderly, the socially deprived and those with poorer self-identified health tended to express the greatest reservations. The survey also reported a wider variation in the ability to manage their illness among the chronically ill than in any other patient group, and suggested that a blanket approach to patient self-management might fail if these major variations in the patient knowledge base were not heeded. Bessell et al (2002) report that, compared to other patients, people with a chronic disease make the most effort to locate health information.

In the case of CHD patients, several studies report that patients felt they had not been given sufficient information concerning their medical condition and that the information they had received was not personalised in such a way as to meet their social, cultural or medical needs (Amanda et al, 1998; Kennelly et al, 2001; McCallum et al, 2001; Richard et al, 2005; Marie et al, 2006; Netto et al, 2007).

In terms of what is known about the sources patients prefer when seeking knowledge about their medical condition, a number of surveys reveal that the UK population in general tends to seek health information most readily from 3 main sources: their GP, other health professionals and close friends and family. All other information sources such the internet, written information and the media are less popular, although written information is also reported to figure strongly among chronic disease patients (Sillence et al, 2006; Munro et al, 2000; Coulter et al, 2006).

Information-seeking among 15,000 randomly selected people was examined in a survey conducted in 1998 in three NHS Direct catchment areas prior to the NHS Direct phone health-line set up (Munro et al, 2000). In the 4 weeks prior to being asked, 52% of respondents reported having sought help or advice for a health problem: 17% of respondents had sought help or advice from their GP, 12% from high street chemists and another 11% from family and friends, with all other methods accounting for 12% in total. In 2003, Mori polled the public on a similar issue, asking where respondents had received health information in the preceding six months: the top three mentions

were the family doctor/GP (35%), family, friends and colleagues (28%) and the practice nurse (21%). Health books and magazines also featured quite strongly, referred to by 21% of those asked; only 10-15% of respondents looked for information from the pharmacist, television, leaflets, websites and hospital doctors respectively. Health workers other than GPs received fewer mentions, as did community groups. NHS Direct online and their phone line featured least frequently, mentioned by only 2-4% of respondents.

In a phone survey, 3,000 people with chronic conditions were asked where or from whom they sourced their health information (Coulter et al, 2005). The results showed a much larger percentage of people reporting that they consulted their doctor to seek information (73%) compared to studies of the general population, perhaps reflecting that a chronic disease patient tends to have a more frequent exposure to their GP than the general population, due to the regular visits usually required by their condition and their long-term prescription medication intake. The internet (30%), leaflets and books (23%) and newspapers (18%) also featured more strongly in this survey as chosen information sources, possibly reflecting the fact that, as people with a chronic disease live with their condition over many years, they are also more likely to seek knowledge about their condition over a longer time span compared to someone with an acute or infectious condition (Bessell et al, 2002). Family and friends were mentioned as sources of medical information by 19% of those asked, with Coulter et al reporting that this figure was higher for people in social grades A and B (26%) than grades C and D (15%).

It is interesting to note that in all three surveys quoted above, both GPs and family and friends always featured among the most frequently cited information sources.

2.2 Online information

Research into patient usage of online information sources shows how uptake is spreading, albeit unevenly, through the population: by 2010, 73% of UK households had an internet connection and 60% of the UK population was accessing the internet once a day - double the figure calculated for 2006 (ONS, 2010). Statistical trends suggest that all ages and social classes appear to be increasing their internet access and usage over time, with people from higher social grades and younger people leading the way as 'early adopters'.

It is known that the likelihood of using the internet currently declines with increasing age, but there is evidence that this may become less significant over time. In 2006, Coulter and Ellins reported that 19% of over 65s reported possible internet use, compared to 50% of 40-64 year olds: however, by 2010, 40% of over 65s had accessed the internet, as had 99% of 16-24 year olds (ONS, 2010). There is also a strong correlation between internet usage and social grade: in 2005, 50% of ABs used the internet compared with 22% of DEs (Coulter et al, 2006). By 2010, the ONS reported that 97% of adults educated to degree level had accessed the internet, compared to just 45% without formal qualifications.

Health-related web traffic is increasing in volume over time: factors identified to account for this include time constraint in the consultation room (Williams et al, 2003); patient desire to complement the information received from a medical professional (Stevenson et al, 2007); patient desire to find alternative information so as not to let the physician dictate their care (Sieving, 1999); and patient desire to be in better control of their health by seeking social and emotional support (Nicholas et al, 2003).

Research on the use of internet websites tends to look more qualitatively at *why* patients seek specific types of health information, compared to non-web health-related research. Online health information is appreciated by the public for being quick and easy to access and is viewed as supplying the knowledge not routinely provided by health professionals (Nicholas et al, 2003). It is associated with people feeling greater confidence to make health-related decisions and participate during clinical consultations (Eysenbach, 2004; Sillence et al, 2007a). The majority of those using health websites are reported to cross-check the information they find with doctors, as well as family and friends (Sillence et al, 2006).

However, studies also show that the public are often overwhelmed by the online information available, due to the quantity of health websites available, coupled with the problem of identifying what information is medically accurate (Damman et al, 2009; Coulter et al, 2006). Whilst some studies report that people seeking health information prefer to use websites of recognisable authority, such as those published by health organisations or professional groups (Eysenbach et al, 2002; Schwartz et al,

2006), many other studies report that, in practice, people browsing for health information online are in fact less discriminating in their choice of web material (Greenberg et al, 2004; Peterson et al, 2003; Cline et al, 2001). The same study authors expressed concern, as much online health-related material was found to be medically inaccurate or misleading.

An interesting trend was noted in a series of papers based on surveys of internet users seeking health-related information: the authors identified an increase over time among web users taking an interest in personalised health advice that matched their own social identity, 'written for people like themselves' (Sillence et al, 2004). Such consumers preferred to use search engines rather than following website recommendations from healthcare professionals (Sillence et al, 2007a), suggesting an active decision on the part of the health consumers to browse according to personal choice rather than medical recommendation.

An analysis of online content concerning the control of hypertension found that alternative remedies dominated the lay literature about hypertension treatment, but that such information was not addressed on mainstream medical websites (Dunn et al, 2001). This suggests that mainstream medicine may be eschewing discussion and analysis of complementary and alternative medicine, despite its popular appeal, in ways that encourage patients to seek information about it from less scientifically reliable sources. This was followed up in the patient study.

3. PATIENT KNOWLEDGE AND ADHERENCE TO MEDICATION

A patient's personal beliefs about medication have been shown to be the most important determinant of whether and how prescription medicines are taken (Horn et al, 1999). A systematic review of medication adherence showed that non-compliance affected as much as half of all medicines prescribed for chronic conditions (McGavock et al, 1996); and intentional non-adherence to prescription medication was identified as a major cause of excess morbidity and mortality (Carter et al, 2003). It was noted in a study by Makoul et al (1995) that the GPs interviewed rarely discussed a patient's attitude or ability to take medicines when prescribing to them; when questioned, patients reported feeling unable to discuss with their doctor reservations they had about whether and how they should take prescribed medication (Levenson, 2003).

Research specifically on CHD patients and medication adherence is mixed, with some studies reporting good patient adherence to prescription medication (Karner et al, 2002; MacDermott 2002), whilst other studies report that cardiac patients regularly omit, alter the dosage, or forget to take their medication, often citing unpleasant side effects as the reason (Haugbolle et al, 2002; Tolmie et al, 2006).

4. PATIENT-RELATED KNOWLEDGE MANAGEMENT INTERVENTIONS

By far the largest volume of literature relating to patient knowledge focuses on the evaluation of specific knowledge management interventions designed to help educate or motivate patients to manage their chronic disease more effectively.

The studies reported below are not exhaustive: many intervention studies lack the numerical power or methodological rigour to withstand close scrutiny. In 2006, Coulter and Ellins published a comprehensive review of the literature on patient-focused interventions for the Picker Institute and noted that this area of research was prone to wide variations in research quality. Recurrent problems were identified in much of the research: study methodology was often flawed and inadequate for the intended task; quantitative study samples too small to be able to demonstrate statistical significance; studies were often too short in duration to demonstrate anything other than very short-term effects, despite making claims that would require longer term follow-up.

In recognition of these methodological problems, the following review reports on systematic reviews of the literature where possible, where reviewers have had the time and resources necessary to evaluate the methodological reliability of study findings, thus producing greater validity in their aggregate outcomes.

4.1 Self-help groups and peer support

Large numbers of self-help groups have been set up to help patients manage chronic conditions, by the NHS and other health-related organizations, by the voluntary sector and by patients themselves. However, three systematic reviews of the literature on self-help groups report that such self-help groups have only a small impact on health status or hospitalization rates (Campbell et al, 2004; Eysenbach et al, 2004; van Dam et al 2005). There is some evidence reported of improved patient knowledge, and an increased sense of social support, but only among women participants: it is interesting to note that in van Dam's systematic review, self-help groups appeared to show a negative effect on the men who took part.

4.2 Lay-led self-management programmes

In 2007, a Cochrane systematic review of a very large literature relating to lay-led self-management programmes for people with chronic conditions, analysed 17 randomised controlled trials that compared lay-led self-management programmes for chronic disease programmes against no intervention or clinician-led programmes (Foster et al, 2007). The authors concluded that, when all the results were assessed and weighted for their statistical significance, any conclusion drawn had to be fairly modest: it could only be stated with certainty that lay-led self-management programmes could lead to small, short-term improvements in participants' self-efficacy, self-rated health, cognitive symptom management and frequency of aerobic exercise. There was no evidence that such programmes improved the *actual* health of those on the programmes, such as psychological health, symptoms or health-related quality of life,

nor was there evidence that such programmes significantly altered healthcare use. Further research was recommended to properly evaluate longer-term patient outcomes and the effect on clinical measures of disease.

A review of the literature by Newbould et al in 2006 examined 17 articles and 2 conference papers on the subject of lay-led self-management programmes, with particular reference to the lay-led self-management programmes for chronic disease patients based on interventions developed by Kate Lorig in the USA and adopted by the UK Department of Health as the Expert Patient Programme (EPP). The review concluded that there was some evidence of short-term benefits derived from such programmes when it came to patient self-efficacy. However, the report also noted that advocates of lay-led self management programmes risked overstating the evidence for their effectiveness and that the range of patient experience involved in chronic disease management militated against any kind of blanket prescription of what such patients ought to think and do.

This concern was echoed in a national evaluation of the Expert Patients Programme, which noted the shortcomings in taking only one approach to chronic disease management, and recommended that resources for supporting patient self-management should be directed at a range of interventions, rather than a single method (Rogers et al, 2008). A 2009 qualitative study of the EPP found only modest improvements in self-efficacy, along with no change in patient use of primary care services and outpatient attendances; nor was there any change detected in patients'

pre-existing self-care activities (Kennedy et al, 2007).

4.3 Chronic disease management programmes

A meta-analysis of a range of interventions aimed at helping patients manage or prevent a chronic condition examined 118 such disease management programmes in studies published between 1987 and 2001 (Weingarten et al 2002). The study revealed that, while 70 out of 118 programmes used more than one intervention, patient education was the most commonly used intervention, included in 92 out of the 118 programmes examined. In terms of patient-related outcomes, 24 of the 55 programmes that used patient education were reported to significantly improve disease control, with patient education itself producing a small but significant improvement in disease control. 16 programmes used patient reminders; six reported a small but significant improvement in disease control. 4 programmes included financial incentives for patients; 3 of these were reported to show significant improvements in disease control. The authors of the meta-analysis reported that all the interventions were associated with improvements primarily in *provider adherence* to practice guidelines and disease control, and that there was an overall paucity of information on the effectiveness of the different types of intervention regarding patient adherence. Study findings were severely limited by data quality, notably the quality and heterogeneity of the original studies and the original metrics used in each study. This author would also add that the study durations were too short to allow for a proper evaluation of the long-term outcomes that are central to effective chronic disease management.

4.4 Rehabilitation programmes for CHD patients

Cardiac rehabilitation programmes (CRPs) represent one of the largest targeted health interventions among chronic disease patients aimed at improving morbidity and mortality outcomes. Economic studies find that CRPs are cost effective compared to the costs associated with no cardiac rehabilitation (BHF, 2010b; Taylor et al, 1997). These programmes are generally organized around groups of cardiac outpatients following release from hospital care. They consist of a 6-12 week course of lifestyle counselling, nutritional advice, weight management and exercise classes, with the aim of preparing the cardiac patient for a return to daily life following a major health event that may have shaken their faith in their physical and mental capabilities.

The NHS National Service Framework for Coronary Heart Disease states that only three of the many diagnostic patient groups that might benefit from cardiac rehabilitation are eligible: those who have suffered a heart attack, had angioplasty or a coronary artery bypass, but even these groups are not all invited to attend a cardiac rehabilitation programme (CRP). According to a British Heart Foundation audit, only 40% of people who had a heart attack and 28% of people who had angioplasty in England, Wales and N. Ireland were actually entered into a CRP in 2008-09: in other words, only 56,589 out of 138, 258 eligible cardiac patients (BHF, 2010b).

The greatest collective patient improvements measured over the course of the 6-12 week CRP are patient activity levels, maximum level of effort and health-related quality of life: the biggest quality of life gains are reported to be in patient physical

fitness, overall health, social activities and daily activities (BHF, 2010a). However, it is unclear how long these effects last once rehabilitation classes cease. Successive CRP audits also show that CRPs appear not to affect the percentage of patients classified as clinically obese: this figure remained static at 27% of the audited patient population in the 2008-09 audit (ibid.). Nonetheless, studies show that the secondary preventive effect of CRPs can lead to longer term survival among cardiac patients, as well as alleviating some of the chronic symptoms of heart disease (Jolliffe et al, 2001; Hedback et al, 1993; O'Connor et al, 1989; Marra et al, 1985).

4.4.1 Drop-out rates

Patient drop-out rates, coupled with the widespread lack of availability of rehabilitation programmes, are found to undermine the significant risk reductions that CRPs offer cardiac patients. Recent research tracked more than 30,000 Medicare patients over 65 years of age for four years (Hammill et al, 2010). After taking into account age and other differences among cardiac patients, the study reported that those who had completed all 36 sessions of the rehabilitation programme had a 47% reduction in the risk of death from any cause, and a 31% risk reduction for a heart attack in the subsequent four years, compared with those who attended just one session. However, only 18% of the patients who enrolled in the programme attended all 36 sessions, a large drop-out rate similar to findings in many other cardiac rehabilitation studies: the literature reveals that reported rates of take-up of CRPs range from 15-59% (Pell et al, 1996) and that 20-25% of patients drop out of exercise

programmes within the first 3 months and 40-50% drop out between 6 and 12 months (Oldridge, 1982).

A variety of predictors for non-attendance that relate to patient or service provision are reported: patients who are female, younger or who have a higher perception of personal control and a lower illness perception of treatment control are less likely to attend a CRP (Yohannes et al, 2007); old age, low income and a low belief in the idea that they can influence disease outcome have also been found to increase the likelihood of patient non-attendance (Cooper et al, 2007); and long travelling distances, poor public transport and poor parking facilities have also been identified as increasing non-attendance rates (Mosleh et al, 2009).

4.4.2 Value of CRP component parts

Health behaviour is complex: improving patient understanding of health issues has not been found to necessarily result in better health outcomes (Lorig & Holman, 2003). Relatively little is known about exactly which aspects of a multi-component approach to improving health behaviours works on occasions, and why.

Although studies show that an increase in patient knowledge is insufficient to change patient behaviours or lifestyle (White et al, 2010; Gambling, 2003; Karner et al, 2005), it is not clear from studies exactly what role patient education *does* play in improving health outcomes. Educational interventions have been shown to improve physician performance and possibly patient outcomes (Davis et al, 1992). In one meta-analysis

of chronic disease interventions, patient education produced a small improvement in disease control (effect size 0.24, CI 0.07-0.40) (Weingarten et al, 2002).

Three major systematic reviews of the CRP literature, including a systematic review of exercise-based rehabilitation programmes for coronary artery disease (Brown et al, 2003), a meta-analysis of secondary cardiac prevention programmes (Clark et al, 2005) and a Cochrane review of exercise rehabilitation programmes for heart failure patients (Rees et al, 2004) all report that rehabilitation programmes with educational and psycho-social components but *without* an exercise component reduce all-cause mortality rates following a heart attack by about 13%. The addition of an exercise component to the CRP reduces all-cause and cardiovascular mortality rates by about 25% (Cooper et al, 2002).

A meta-analysis of 28 controlled trials to assess the effects of patient education on cardiac morbidity and mortality, showed that patient education had a positive effect on patient exercise, diet, blood pressure and mortality rates, but had no statistically significant effect on smoking, drug adherence, patient morbidity or return to work (Mullen et al, 1992). However, neither the strength nor the duration of the effect of education on each factor was clear from the meta-analysis.

A number of studies note that a significant minority of CHD patients are also likely to develop their own informal methods of self-care in addition to the advice they receive as part of their formal cardiac rehabilitation programmes, most notably the use of

complementary and alternative medicines (Greenfield et al, 2008; Barraco et al, 2005; Wood et al, 2003).

4.4.3 Psychological interventions

There is a large volume of literature that examines the effect of psychological stress on CHD and the negative effects of stress on the heart, as well as the role of resilience in reducing the magnitude of health effects associated with stress (Dimsdale, 2008). However, the health effects of stress management interventions on patient health are less clear: a systematic review of the literature reports that psychological interventions, especially stress management, show no evidence of effect on total or cardiac mortality, but do show small reductions in anxiety and depression in CHD patients (Rees et al, 2004). The author of the systematic review also noted the poor quality of the trials, the range of trial types and evidence of significant publication bias, as these factors rendered unreliable the finding of a reduction in non-fatal heart attacks as a result of psychological interventions.

4.5 Patient access to health records

A number of studies have investigated the proposition that patient involvement in self care can be improved by increasing patient access to their personal medical information. A systematic review of the literature revealed that such studies provided some evidence that retaining health records increased a patient's sense of control, but little evidence of any beneficial effect on either their health behaviour or health status (Coulter & Ellins, 2006). Some smaller studies suggest that the clinical information

contained in patient health records is better appreciated when integrated with patient-provider communication and information involving ongoing, active care (Ralston et al, 2007; Hassol et al, 2004).

There have been major setbacks in government plans to provide online access to patient health records. The Department of Health suspended its accelerated introduction of online Summary Care Records in five UK health regions in April 2010, following opposition from the BMA. In June 2010, a 3-year evaluation of online summary care records and the online patient health portal *Healthspace* reported only modest benefits, coupled with little evidence of patient or clinician uptake and a technically complex and 'top down' method of implementation (Greenhalgh et al, 2010). The new Health Minister Andrew Lansley announced later that year that work on summary care records would continue, but would only provide the minimum information necessary for emergency treatment. It remains to be seen whether such online records will finally be introduced and how they will be utilised.

4.6 Patient-centred telecare

Telecare has become an umbrella term for the use of telecommunications technology for medical diagnostic, monitoring or therapeutic purposes, where distance separates the user from the diagnostic expert. Telecare is viewed by its advocates as a vital part of the array of consumer-facing technology that can help bring patient care out of the hospital and into the home. A systematic review of the literature suggests that home-based telecare interventions tend to improve patient self-care (Hersh et al, 2006).

However, the considerable interest in the development and marketing of telecare devices in the private sector has met with less enthusiasm on the ground from practitioners, who have yet to be convinced of the potential for efficiencies of cost and staff time. The interim results relating to the cost effectiveness of telecare are very mixed and highly debated. Results are often further complicated by the range of applications included in the term and the varying methods of calculating the savings and costs attributed to their usage.

The Department of Health is currently conducting the largest UK randomised control trial of telehealth and telecare, involving 6,000 service users over 2 years, in a real-time study to assess the impact of assistive technology in addition to standard treatment. The study is due to report its findings in 2012.

4.7 Interactive Health Communication Applications (IHCAs)

IHCAs are web-based patient information packages that combine health information with social support, decision support and behaviour change support for the user. A systematic review of the literature assessed the effect of IHCAs for people with chronic disease (Murray et al, 2004). 24 randomised controlled trials, involving 3,739 participants were included in the review, which concluded that IHCAs had a statistically significant positive effect on patient knowledge, social support and clinical outcomes. However, small sample sizes in the studies examined undermined the reliability of the statistical evidence. Seven trials of computer-based systems for people with chronic diseases all reported positive effects on self-care behaviour among the participants,

but further research is required to identify exactly what makes IHCA's effective for chronic disease patients, as well as the extent to which IHCA's actually improve clinical outcomes.

A study conducted by Kaiser Permanente's Centre for Health Research reported that overweight people who lost weight and then consistently logged on to a specially designed interactive website were able to maintain a significant proportion of their weight loss better than people who logged on less often (Funk et al, 2010). The website was designed to reinforce existing behavioural self-management skills, encourage new ones, improve self-monitoring, encourage long-term use of the website through using innovative content and promote social support from other website users and personal counselling. The logical flaw is evident: it might equally be argued that this is a case of reverse causation, where those most motivated and determined to maintain their weight loss were more likely to continue to access the website, rather than the website itself providing the motivation. Other studies have also found statistically convincing correlations between self-monitoring and weight loss maintenance (Perri et al, 1989; Kayman et al, 1990; Hartman et al, 1990), although none has proved the direction of causation.

4.8 Contracts between patients and healthcare practitioners

A health contract is a written contract between a doctor and patient that promises a patient a certain standard of treatment in return for following their doctor's advice and attending appointments. The aim is to try and increase patient adherence to

medical advice, particularly in the area of health behaviours, as poor patient adherence is often associated with treatments that take a long time, have side effects or involve changing a patient's habits, all of which are common features of chronic disease management. The idea was heavily promoted in Labour Party health circles in 2003, but has not been encouraged to date in NHS healthcare. A systematic review of the literature examined whether contracts between practitioners and patients improved either patient adherence to treatment or their health status (Bosch-Capblanch et al, 2007). The authors included thirty trials, all conducted in high income countries, involving 4,691 participants: they concluded that the evidence available was too methodologically unreliable to prove or disprove the effectiveness of doctor-patient contracts in improving patient adherence to treatment or preventive health regimes.

4.9 Health Behaviour Modification

Studies in human behavioural research report that, where immediate gratification conflicts with longer-term goals, it is usually the short-term temptations that prevail (Herrnstein 1996; Rachlin, 1995). This is confirmed in studies of lifestyle behaviours, such as dieting and smoking (Baumeister et al, 1996). When people are faced with a choice that could yield either short-term satisfaction, or longer-term benefits, people with the most complete information concerning their options still tend to opt for the short-term reward over and above the longer-term benefit, thus making it harder to reinforce the rewards of long-term benefits such as improved health behaviours (Otto et al, 2010).

Health professionals actively engaged in health education are reported to feel pessimistic about the effects of health education on patient health behaviours. An examination of attitudes to cardiovascular health promotion among GPs and practice nurses revealed considerable scepticism: most felt they were not influential in helping people to change their lifestyles when it came to smoking, physical inactivity and obesity (Steptoe et al, 1999). Such scepticism may also affect what happens in the consultation room: a 2005 study found that when people visited their GP, 44% felt that their doctor did not encourage them to play a more active role in staying healthy or in managing long-term health conditions (Department of Health, 2005d). A survey of 1,000 US patients found that only 39% of clinically obese patients were actually informed of this by their doctor, while 290 primary care doctors in the US reported that many did not feel able to adequately address problems of obesity (Harris Interactive, 2009).

Studies investigating patient knowledge about modifiable risk factors and long-term health maintenance fail to demonstrate a clear association between the two³. In terms of the literature relating specifically to CHD patients, two general themes emerge: firstly, that some but by no means all patients manage to maintain some lifestyle changes following a major event such as a heart attack (East et al, 2004; Gambling, 2003; Wiles, 1998; Wiles et al, 2001). Secondly, patients usually experience

³ Health maintenance is the term used here to describe patient management of modifiable health behaviours, as recommended by the NHS: in the case of CHD patients, these factors include advice on diet, increasing exercise, reducing alcohol intake and smoking cessation.

difficulty in making and maintaining lifestyle changes (White et al, 2010; Gambling 2003; Karner et al, 2005; Sjöström-Strand et al, 2007; Thomas, 1994; Tobin, 2000).

Patient comprehension of the reasons for his or her heart attack appears to influence their decisions about making lifestyle changes, as those who do not identify a lifestyle cause for their heart attack are reported to show more difficulty with lifestyle-related health maintenance (MacInnes, 2005; Thomas, 1994). Some research identifies insufficient knowledge and information as the reason for a patient's poor health behaviours, citing as examples a patient not knowing *how* to replace fat intake in the diet, or a patient attempting to change too many behaviours at once, or overprotective family behaviour towards the patient preventing sufficient physical exercise (Karner et al, 2005; Condon et al, 2006).

By contrast, other studies report that educating patients is in itself unlikely to alter their long-term behaviour (Coulter et al, 2007; Robertson, 2008; Editorial BMJ, 2008).

Men seem to be particularly resilient to improving their health behaviours, with younger men thinking it too early, and older men thinking it too late to make the necessary lifestyle changes (Meillier et al, 1996; Ritchie et al, 1994). A study of a group of people who knew they were at increased risk of CHD showed their attempts at lifestyle modification to be limited, particularly where any such modification might affect their quality of life in the present (Bach Nielsen et al, 2005).

Social epidemiologists state that effective changes in patient behaviour require interventions at several levels, from individually managed behavioural interventions, to those that address the 'upstream' social determinants of health, such as the social and environmental factors that can support the required lifestyle and behavioural changes or render them hard and impractical to achieve (Marmot et al, 1999; Stokols et al, 1996). This clearly goes far beyond what it is in the power of GPs to prescribe and suggests that the health maintenance aspects of chronic disease self-management cannot be viewed as a solely medical matter.

4.9.1 Obesity

Studies examining health behaviour modification such as weight reduction tend to focus on short-term outcomes, which are often of limited value when trying to establish the effectiveness of interventions aimed at long-term chronic disease management. Studies on obesity are a good example of the problems of studying effective interventions aimed at managing long-term lifestyle modification. Obesity is a major risk factor for CHD and many other chronic diseases, but when it comes to the study of weight loss treatments for obese patients, the average length of medical intervention is 18 weeks and the average weight loss about 9.9 kg (Foreyt et al, 1993). Around 66% of people who lose weight maintain their weight losses at 52 weeks of follow-up; but the persistent problem shows in follow-up studies after 3 to 5 years, when there is a gradual return to baseline weight (Brownell et al, 2000).

Two recent studies from the Medical Research Council (MRC) report better and longer-lasting results among obese patients who are referred to commercial weight loss programmes when compared with those on standard NHS weight management programmes. The first study monitored participants over 2.5 years: they received NHS vouchers to attend 12 Weight Watchers meetings paid for by their Primary Care Trust. 60% of patients completed the course, with more than half losing 5% of their body weight, which is considered a clinically significant amount in terms of delivering health benefits, although the study does not report whether the participants were satisfied with these results (Poulter et al, 2007). The second study was a large-scale RCT in 3 countries including the UK, comparing the effectiveness of Weightwatchers, a commercial weight loss programme, with 12 months of standard care weight loss provided by a GP, involving diet information sheets and clinic nurse appointments for weigh-ins and advice. 36% of those referred to Weight Watchers lost 5% or more of their original body weight, compared to 16% of patients on standard GP care (Jebb, 2010). Further research is required to establish the reason for the difference in outcomes: the study author attributes it to the increased social support participants received in the commercial weight loss group, in the form of additional motivation from other participants in the diet group, who were observed to encourage participants even when they had had major lapses in their regime.

The results do not suggest that commercial weight loss companies are a universal panacea: the study achieved results over 12 months for only 36% of participants. Around 90% of participants were female. The study acknowledges that such group

approaches hold little appeal for the majority of men and that Weight Watchers classes are overwhelmingly white, even in areas with significant minority ethnic communities. Other approaches will need to be studied for their effectiveness and 'reach': however, the MRC obesity studies suggest that it may prove both medically and financially effective to transfer the management of health behaviours out of the GP surgery into the hands of people whose professional focus and expertise lies specifically in behaviour modification and health maintenance.

As obesity is a chronic condition with a strong tendency towards relapse, longer-term treatments are needed, as are longer-term studies of those treatments. The tendency towards small short-term studies can also lead to false expectations: for example, an RCT in Newcastle in 1999 investigated how physical activity might be increased among obese patients (Drinkwater, 2007). 532 people were invited to take part, some given one-to-one motivational talks about increasing their physical activity and others given motivational talks and free vouchers for use in leisure centres for the duration of the three-month study. After three months, 55% of those who had been given motivational talks and vouchers had increased their level of physical activity, compared to 35% who had only received the chats. However, a year later researchers found that the short-term increases had not been sustained and showed no long-term benefit. A three-month study would have failed to record the return to baseline levels of inactivity: such accounts provide good examples of why short-term results provide little or no clue as to the long-term effects of health maintenance interventions.

4.9.2 Blood pressure monitoring

Blood pressure monitoring is a good example of CHD patient clinical self-management that has been made possible through the easy availability of low-cost but reliable blood pressure monitors. One recent study examined the longer-term effect of patient self-reported blood pressure monitoring, and reported that the act of taking daily blood pressure readings over one year registered a statistically significant drop of 17.6 mm Hg in systolic blood pressure among hypertensive patients who managed their own care, while patients on standard therapy saw a 12.2 mm Hg drop (McManus et al, 2010). The self-managed patients had attended two training sessions to learn how to use the BP monitors and relay the information to the surgery via an automated modem device. The study authors explained the difference in outcome by suggesting that those patients who had been randomly assigned to self-reporting their blood pressure had appeared to take a more active role in trying to reduce it.

A recent meta-analysis of 37 international clinical trials also concludes that home monitors could help control blood pressure more effectively than visits to the GP surgery (Agarwal et al, 2011). The study found that, on average, adults with high blood pressure who were given home monitors, managed to reduce their blood pressure by 2 to 3 points compared to patients who attended their GP surgery for blood pressure readings. The home monitor users were also twice as likely to reduce the number of blood pressure medications they were taking. Telemonitoring, where readings were sent electronically to the doctor's surgery, showed the greatest positive effect on patient blood pressure.

4.10 Current interventions and lack of evidence base

There are a number of small-scale NHS one-to one support-based interventions currently used in different parts of the UK to support behavioural change in people with chronic conditions. These include interventions around goal setting and action planning; buddying schemes; coaching and counselling; relaxation techniques; motivational interviewing; cognitive rehearsal and other health maintenance strategies. Apart from the obvious drawback that they are generally labour-intensive and therefore costly, there is little or no systematic evidence available that can help determine which one or combination of these interventions may actually prove effective in changing behaviours and in which population groups (Boyce et al, 2008). The Department of Health has spent £77 million a year on health trainers since 2008 in order to support behaviour change through providing selected patients with six one-hour one-to one counselling and support sessions: an independent evaluation is due for publication in 2011, which may or may not be long enough to capture the problem of return to base-line.

4.11 Public health campaigns

The public health approach to addressing population level health behaviours has proved singularly unsuccessful in key areas of behaviour modification.

Many government-led public health initiatives have been targeted at encouraging behavioural change in the viewer or listener: a health problem is identified, an

organisation is paid to devise and promote a solution, usually organised around an expensive public awareness campaigns to proselytise a 'message' in order to educate viewers and listeners into changing their ways. Such public health campaigns are usually predicated on knowledge-deficit theory: that is, that the problem is caused by a lack of knowledge in the individual and that an increase in that individual's knowledge will trigger the desired change in behaviour. The familiar annual drink driving advertising campaign is considered a relatively effective example of the knowledge-deficit model: the campaign works on increasing awareness of the personal consequences of a drink driving conviction and reinforcing the social stigma around drink driving. It is associated with considerable success in reducing drink-driving: compared to 1980, there were 75% fewer drink-drive related fatalities in 2010. However, the knowledge deficit theory works considerably less well when it comes to health behaviour campaigns.

In the 1990's, the campaign *Active for Life* failed to generate any measurable increase in the UK population's physical activity, despite extolling the virtues of exercise to the general public (Hillsdon et al, 2001). Mass media campaigns aimed at encouraging people to change their smoking, diet and exercise habits, have at best been found to improve individual knowledge and change beliefs about health related activity, rather than being directly responsible for changing behaviours (Flynn et al, 1992).

On gaining office in 2010, Health Secretary Andrew Lansley was critical of the *Change for Life* campaign launched under the previous Labour Government, a campaign which

aimed to encourage families to eat more healthily and take more exercise together. Lansley cited a lack of evidence that such public health campaigns actually worked: it is hard not to agree with this assessment, in view of both the past history of healthy eating and exercise campaigns as well as the known complexity of the relationship between patient knowledge and health behaviours set out above. It remains to be seen whether Government health campaigns based on more recent 'nudge' theory will fare any better.

5. PATIENT KNOWLEDGE CREATION

Our attention now turns to specifying what the existing literature contributes to our understanding of whether CHD patients generate knowledge in the course of managing their condition.

5.1 Collective and individual knowledge

KM theory advances the idea that communities of interest - communities formed around the common practice of a specific activity - can deliver benefits to an organisation by providing an environment for generating and sharing information and knowledge (Wengler et al, 2002).

The output from patient communities of interest can sometimes be found in the reports of NHS Service Improvement Managers and Patient Co-ordinators, in the form of complaints or feedback opinion in response to agendas set elsewhere. In healthcare,

knowledge generation and research output is usually conducted separately from medical practice. Martin et al (2009) attribute this entrenched cleavage to the considerable academic and financial power attached to the generation of medical knowledge: this may also help explain why patient-generated knowledge and learning has only relatively recently been attracting some attention.

Patient knowledge is also a very different form of knowledge from the 'gold standard' knowledge produced by the Randomised Controlled Trial (RCT): patient views are of necessity subjective, and they generally lack awareness of the scientific method, so their value as knowledge producers is thrown into doubt for much of the scientific community.

In his book *The Wisdom of Crowds* (2005), James Surowiecki states that 'groups are remarkably intelligent, and are often smarter than the smartest people in them' and illustrates this with examples such as one showing how the collective decisions of individuals can prove superior and more profitable than professional stock market expertise. This 'collective wisdom' thesis could be applied to a patient population: when patients share observations about their condition, is it possible that their collective wisdom might yield medically useful insights into their condition?

There is also a social value attached to information gleaned from patients: according to the 2008 Edelman Trust Barometer, people tend to trust 'people like me' more than

they trust figures of authority. This has also been shown to affect how patients search for health information online, where the views and experiences of patients 'like me' are actively sought out. In 2006, Sillence et al identified a growth in the tendency of health consumers to access unregulated health websites when compared to those in a similar survey conducted in 2000. The study noted a measurable shift away from medical expert websites towards sites run by individuals; personalised health advice was seen to increase health consumer trust in its content. The authors suggested that health consumers were searching for sites that matched their own social identity and that were 'written for people like themselves' (Sillence et al, 2004; Sillence et al, 2007a).

5.2 New uses of patient knowledge in healthcare

The author has been unable to locate any existing literature that directly examines the question of whether patients generate new knowledge in the course of managing their CHD. However, examples of patient-generated knowledge are seen in action in a handful of studies into some relatively new online projects that aim to utilise patient knowledge in order to advance medical research.

Patientslikeme is an interesting model of patient knowledge and knowledge management in action. Set up in 2006 by James and Benjamin Heywood, both alumni of the Massachusetts Institute of Technology (MIT), it is an interactive website that

uses open platform social networking methods to serve 16 disease communities: 66,000 patients were online to this interactive website at the time of writing this study.

Patientslikeme has three distinct features: it hosts and analyses individual patient data applications, as well as aggregated patient data and patient-determined medical experiments. Patient-centred applications help patients forecast and manage their individual condition: participating patients are asked to define their symptoms and treatments using hard data, listing their drugs and dosages and then scoring how well these alleviate their symptoms. This data, compiled over time, is turned into bar graphs and progress curves by the website software, showing each patient's progress. This patient clinical and personal data is then aggregated in ways that can be used to measure, compare and analyse treatment outcomes among participating patients, for example, by looking at comparative self-efficacy outcomes according to medication, or relative survival rates based on any number of criteria. Early studies show that patients using the website report a range of benefits that may be related to site usage, including helping patients determine their best possible treatment outcomes, and helping patients to understand side effects associated with specific medication, but that third party and longitudinal evaluation is still required to evaluate its true potential (Wicks et al, 2010; Brownstein et al 2010; Brownstein et al 2009; Frost et al, 2008).

More controversially, patients can also participate in real-life medical experiments where there is sufficient demand to do so. When a small 2008 study suggested that

lithium carbonate might halt the progression of ALS (amyotrophic lateral sclerosis), many patients bought the drug 'off-label' long before medical trials were conducted (Fornai, 2008). In response to patient demand, *patientslikeme* built a live study tool so that ALS patients could record their experiences on lithium, including side effects, perceived efficacy, lithium blood levels and any noted improvements in their condition. Such patient reportage is no substitute for a clinical trial, but the site is able to provide a preliminary real world assessment of how the drug is performing, based on the self-reported data of 433 patients, long before researchers are able to enrol patients, conduct, and report on a follow-up study. The website owners are currently trying to establish data-sharing partnerships with medical and pharmaceutical companies and research organisations, based on the real-world outcome-based patient data collected online.

Similarly, the *LAMsight* venture, set up in 2005 through the LAM Treatment Alliance (LTA) in collaboration with MIT uses a similar model of patient knowledge in action. *LAMsight* describes itself as a 'not-for-profit project intended to foster collaboration, impact and data access among all members of the LAM community – patients, researchers, and clinicians.' LAM, or lymphangioleiomyomatosis is a rare fatal disease that affects women and attacks the lungs, kidneys and lymphatic system; but it is the purpose of the interactive website that is of interest here. LAM patients can use a purpose-built website to report information about their health and disease progress, which is added into a database that can be searched for observations about the

disease. Data consisting of individual patient observations can be aggregated and analysed to help generate new hypotheses and guide research.

These first examples of open source patient-generated data for medical research purposes raise three topics of direct interest to this study: firstly, they demonstrate that patient knowledge, arising out of the experience of living with a disease, may have new types of value associated with it now that the technology is available to easily harvest some of that experience. Secondly, they suggest a new type of relationship between researchers, patients and doctors, where patients develop an active role as research co-producers. Thirdly, they encourage the generation of research that is relevant to the patient. They also throw up significant new methodological problems, such as the ethical implications of companies exploiting patient medical information outside the standard ethical research procedure, and the problem of quality assurance and validity in relation to self-reported patient data.

At this stage, it is impossible to know where this type of innovation may lead, as online applications have shown a distinct tendency to develop in unforeseen ways. To date, this kind of consumer-generated health content has found a relatively small but appreciative patient audience, with a growing range of applications.

6. RESEARCH OBJECTIVES

The literature review identifies how gaps in our understanding of patient chronic disease management are exacerbated by our lack of clarity about the role patient knowledge plays in chronic disease management. So for example, a number of quantitative studies and surveys discussed in this chapter identified the fact that patients report seeking knowledge and information about their condition most frequently from doctors, nurses, friends and family members and the internet, with other sources usually proving less popular. However, quantitative studies cannot tell us *why* patients choose specific knowledge sources. This study will investigate which knowledge sources the CHD patients interviewed select when they wish to seek knowledge and information about their condition, and more interestingly, will examine *why* they choose to do so. The study will examine whether patients are seeking the same information from each knowledge source and if not, whether there are different types of knowledge being sought from different sources. This is particularly interesting in relation to patient knowledge-seeking from friends and family, as they tend to be a most unlikely source of the kind of knowledge one might expect patients to seek who are trying to manage coronary heart disease.

The existing literature on patient internet usage was divided about whether patients were seeking authoritative expert knowledge, or something more subjective and personalised. Patient attitudes to internet knowledge-seeking will be explored with this division in mind. Patient attitudes to knowledge-seeking in relation to their

personal health record will also be examined, bearing in mind the current plans to create online summary care records.

The existing literature reports significant differences in outcome regarding the effect of patient education and knowledge on patient compliance and chronic disease management: the study will seek to research this area further and investigate the role knowledge plays in the decisions taken by the CHD patient cohort, specifically in relation to drug compliance and long-term health maintenance.

Patient chronic disease management is perhaps the area of patient healthcare where shared knowledge management needs are most acute: the last major studies into patient self-management were conducted in 2000, so this study will examine the extent to which medical knowledge is currently shared between the doctors and patients interviewed, as well the extent to which health professionals help patients to manage their knowledge and information sources.

The study will also explore patient responses to any of the knowledge management interventions listed earlier in this chapter that they have participated in. As most patients will have had serious cardiac episodes, it is anticipated that many will have been invited to take part in a cardiac rehabilitation programmes (CRPs).

The existing literature on patient knowledge creation is extremely sparse: interest in this area of patient knowledge is still very recent, and motivated primarily by new technological possibilities for patient data collection and analysis afforded by interactive web software. This study will examine what evidence there is among CHD patients interviewed of knowledge generation taking place among CHD patients that may be of wider organisational benefit or of benefit to the CHD patient population as a whole. It will also try to identify what form such patient-generated knowledge takes.

In summary: the above-mentioned gaps and contradictory outcomes in the existing literature justify embarking on the new research that follows, and help to establish specific areas of interest in the planned research into patient knowledge-seeking, patient knowledge generation and its implications for knowledge management interventions aimed at CHD patients.

7. RESEARCH VALUE

Knowledge management emphasises the value of understanding how organisational learning occurs and what benefits can flow from this learning; however, patient knowledge, in terms of both patient knowledge-seeking or knowledge generation, has been largely absent from health-service based KM initiatives (Nicolini et al, 2007). Policy debate often proceeds on the assumption that the actions of health professionals are the sole determinants of health outcomes, although there is some evidence that this is beginning to change in places.

Direct contact with health professionals constitutes only a small part of any chronic disease episode for a patient: patients themselves, and their carers where needed, provide the majority of healthcare. In this role, they require education and decision support just like other members of the health care workforce. Whilst some critics assume that the desire for greater involvement in self-care centres on a minority group of young, white, middle-class patients, the evidence does not support this. The desire for participation has been found to vary according to age, educational status and disease severity, but these factors explain only part of the variation (Coulter and Ellins, 2006). For example, despite the association between age and decision-making preferences, age on its own is not a reliable predictor of a patient's preferred role. People's preferences may vary according to their stage in the chronic disease trajectory, the severity of their condition or according to often hidden cultural assumptions about illness and human agency.

Clinicians' assumptions about what their patients want have, in the past, often turned out to be wrong: there is a need to understand what role patients could play in the knowledge processes that determine how patients' health needs are evaluated and met. Understanding what and who patients value in the knowledge management process matters, because it helps lead both health professional and patient to a health outcome that stands the greatest chance of success in terms that both the doctor and patient will understand as such.

When it comes to examining patient knowledge creation, there are at least two possible beneficial outcomes to the medical community and patients: firstly, knowledge generated by patients could potentially add value to medical research and learning. Secondly, patient knowledge could help fuel organisational innovation and greater efficacy at the level of clinical services.

At present, there is a policy-driven assumption implicit in health policy literature, that chronic disease patient self-care is largely a matter of unspecified large scale re-education programmes of patients and doctors into accepting new roles and the redistribution of responsibilities. However, past experience in the healthcare sector suggests that new processes can founder on hidden assumptions and unwieldy IT solutions that fail to deliver the outcomes expected of them. It is for these reasons that healthcare providers need a better understanding of the role of patient knowledge in chronic disease management, as a guide to increasing the effectiveness of patient-targeted KM interventions now and in the future.

CHAPTER 4 | METHODS OF THE RESEARCH STUDY

1. INTRODUCTION

This chapter sets out the methodology and methods used in this study. Section 2 below explains the grounded theory method, its work stages and the theoretical considerations relevant to this choice of qualitative approach.

Section 3 sets out the methods used in this study, including the study design and purpose, study setting and study population, relevant ethical matters, patient recruitment and sampling, the development of a complementary GP questionnaire, and data collection and analysis during the 10-month study schedule.

2. METHODOLOGY

The proposed patient research necessitates a qualitative rather than a quantitative approach, as it seeks to examine *why* patients make particular choices about their healthcare, as well as the nature of their contribution to knowledge about chronic disease management. The study needs to be able to investigate participants' feelings, choices and experiences: such matters lend themselves to a qualitative approach (Bowling, 2002; Greenhalgh and Taylor, 1997).

The author chose to use the grounded theory method, as it constitutes one of the more rigorous approaches to qualitative data capture.

2.1 The grounded theory method

The origins of grounded theory date back to the 1960's, to working methods associated with University of California sociologists Barney Glaser and Anselm Strauss, who together conducted a study into patients who died in hospital. Their published work *Awareness of Dying* (1965) is the first application of their grounded theory method, which they continued to develop over several decades.

The theory describes a process for collecting and analysing qualitative data, designed to introduce a less speculative approach to qualitative analysis than had existed heretofore. Yet the grounded method stands in stark contrast to quantitative analysis, which attempts to minimise error and increase validity through the application of rigorous sampling methods and the use of large sample sizes to deliver statistically significant results. By contrast, grounded theory is used to generate theories from data using smaller sample sizes and a greater attention to individual motivation, involving, in Glaser's own words: 'a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area' (Glaser, 1992: pg 16).

Grounded theory cannot be used to test pre-existing hypotheses, as its methodology is

explicitly emergent: instead, grounded theory is itself a method of generating hypotheses that arise out of the close analysis of social research data. This approach militates against the imposition of an *a priori* theoretical framework on gathered data; instead, any hypotheses are based on, or 'grounded' in the data obtained. As such, it is an appropriate method for the kind of research conducted in this study, where the aim is to ignore preconceptions and capture the complexity of the experience of patients with a chronic disease, specifically to hypothesise how patient knowledge-seeking and knowledge generation affects self-care.

From the late 1980's onwards, both Glaser and Strauss published and debated separately their increasing differences regarding grounded theory method and practice. Whilst Glaser has maintained the importance of a 'constant comparative' method, Strauss and Corbin developed a more schematic approach to data coding. Theoretical differences about the relative importance of aspects of data coding developed into insurmountable differences of theoretical and practical approach and a parting of the ways for Glaser and Strauss as research partners. This study uses the more orthodox Glaserian grounded theory methodology, as a method more concerned with analysis and theoretical development than with the rich description more characteristic of Strauss and Corbin.

As set out in the previous chapter's review of the literature, there is already a literature that enumerates the range of knowledge sources that patients seek out: this study will look more closely at what *motivates* patient knowledge-seeking behaviours,

why CHD patients use particular knowledge sources and *what kind* of knowledge they are seeking from those sources.

The topic of health and patient practice has become highly politicised over the last decade; there are many ‘top-down’ assumptions about how increased patient self-care should function, how patients ought to behave and how these factors should contribute to a reduction in spend per chronic disease patient. In this context, it seems useful to try to let the data generated speak without regard for purposes determined by policy considerations, as these can be addressed at a later stage.

2.2 Work Stages

Data analysis and the generation of theory are not separate stages in grounded theory research. As can be seen in the results in chapters 6 and 7, the act of analysing data and generating ideas grounded in this data proceed throughout the study: the key activity is the coding of relevant data and the careful development of conceptual categories. Incoming data is constantly compared to existing data captured; new data is used to refine and validate existing categories or develop new ones where strictly necessary. As in all research, parsimony, the simplest route of explanation available to the investigator, is an important guiding principal.

The investigator’s theoretical sensitivity is developed throughout a grounded theory study, by working through the following phases:

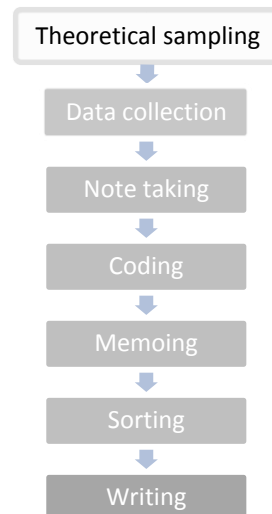


Figure 4.1 Work stages in Grounded Theory

Many of these stages overlap: so, for example, coding, memoing and sorting take place alongside data collection. Note taking takes place throughout the interview period, as categories are developed and refined during the study period itself, rather than after data collection has ceased. This also means that, unlike quantitative studies, design can be adjusted over the duration of the research period in (Miller et al, 2004; Glaser, 1998). So, for example, the interview questions in this patient study were refined throughout the patient interview period. Some questions proved too abstract or self-evident when tried out in practice: offending questions, such as those that asked patients to discuss what role the GP should play in healthcare, were dropped. Other interview topics, such as the patient's experience of health maintenance and their choices of information source proved to be subject areas that patients generally talked about in detail and with ease, requiring less prompting than expected.

Despite the range of knowledge management interventions aimed at patients itemised in the literature, it emerged that the patients interviewed had experienced very few of them. In fact, a subsequent survey of Camden GPs reported in chapter 8 confirmed that remarkably few of these interventions are offered to CHD patients in Camden PCT, even though it is one of the more forward-thinking Primary Care Trusts. The main KM-related intervention, experienced by 10 out of 34 patients interviewed, was Coronary Rehabilitation, which NHS guidelines suggest should be offered following angioplasty or coronary bypass surgery. Otherwise, patients received little knowledge support from primary or secondary care sources beyond verbal or written dietary and/or exercise advice. The author decided against conducting theoretical discussions with patients about interventions mentioned in the literature, and concentrated only on those interventions the patient had actually experienced.

Finally, one topic arose spontaneously and frequently and was of particular concern to patients: namely, the poor quality of care experienced by those who required district nursing or domestic care support in their homes. Patient experience of home health and social care support is therefore included in the results section due to its possible distal effect on patient trust and knowledge-seeking behaviours.

2.2.1 Theoretical sampling

Glaser states quite explicitly that 'Generalising to a larger population....is not appropriate to grounded theory' (1992). As grounded theory method is not concerned with quantitative outcomes, but with developing theoretical categories that help

explain the relevant actions or concepts under investigation, a 'theoretical' rather than a 'representative' sampling method is used. Instead of a one-time sample selection, theoretical sampling involves selecting interview participants throughout the interview period in order to test and refine themes as they emerge during the interview process. In other words, the emerging theory also helps to guide sample selection. Glaser and Strauss explain theoretical sampling thus:

'The process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges.'

(Glaser & Strauss, 1967)

The idea is create a pool of interviewees who are most able to inform the developing categories and emerging theory, thus allowing interplay between theory and data analysis to develop as the data is collected (Coyle, 1997). According to Glaser, an analyst cannot know in advance exactly what type of individuals the sample needs to contain, so they are chosen when they are needed, starting with the most likely interviewees. As concepts are identified, different individuals and situations may need to be sampled in order to strengthen the findings and to further the development of emerging categories and concepts. This kind of sampling method allows for a type of flexibility during the research process that is unavailable to traditional statistical sampling methods (Glaser, 1978).

2.2.2 Data collection

Data collection is the summary term used for all the research activity involved in generating new data, in this case including interviews, questionnaires, patient observation and the collation of the relevant existing literature. An ultra-orthodox Glaserian approach would dictate that existing literature ought *not* to be examined until the study is completed, rather than in advance of the study. However, no patient study can proceed without clear objectives built on some knowledge of the work that has gone before, not least because the research ethics committees that approve or deny access to patients for the purposes of study, require considerable detail about the proposed study well in advance of its execution, including the reason why it is necessary. This demands a familiarity with the existing literature. Strauss paints a more pragmatic picture of the investigator and states instead that prior knowledge should only be brought into play when it coincides with the data generated:

‘Because no researcher enters into the process with a completely blank and empty mind, interpretations, which take the form of concepts and relationships, are continuously validated through comparisons with incoming data. These are then validated through comparisons with incoming data.’ (Strauss et al, 1998)

Face-to-face semi-structured interviews are favoured by Glaser as the research method most likely to generate detailed accounts of the individual’s experience. Such interviews are required to be sufficiently flexible to allow the discussion to move into unanticipated subject areas, rather than be identical in form one to another and reproducible, as would be required in a quantitative study.

Constant comparison, coupled with deviant case analysis was used to enhance the validity of observations captured in the patient study. Constant comparison involves sorting the study data into themed categories: themes from each interview are successively compared to the preceding interview themes, to help refine and enrich the categories identified. Deviant case analysis involves an examination by the investigator of any categories that do not fit the emergent trends evident elsewhere in the study, in order to further refine and delimit prevailing themes and trends identified (Charmaz 2006; Glaser et al, 1967). The researcher is meant to continue this process throughout the period of data collection until saturation is reached, when new information ceases to add substantive new perspective: realistically, many grounded theory scholars acknowledge that the practical considerations of time and budget are equally likely to demand that a halt be called to data collection.

2.2.3 Note taking

Glaser discourages recording or taking notes during an interview or other data collection session, as these processes may disrupt the flow of information between interviewee and investigator. However, this requirement was not observed in this study in the interests of accuracy: a contemporaneous note was taken of all interviews, and further notes were taken immediately after each interview was concluded in order to capture any other observations.

2.2.4 Memos

Memos were used to record ideas that occurred to the investigator in the course of data collection that resulted from a re-examination of the primary data. Interviews were examined to seek similarities and contrasting responses, as well as more abstract conceptual themes latent in the material.

2.2.5 Coding

Coding is the act of breaking down and labelling data – in this case the patient interviews – into basic units of meaning. These codes then help make up the concepts and core categories that the investigator develops. At the initial stage of data analysis, open coding was used to categorise the qualitative data into themes, which was then grouped into descriptive categories. Thereafter, selective coding was used to reduce the data to what is relevant to the study questions. Descriptive categories were re-examined to conceptualise the categories, as the investigator moved to higher levels of abstraction. Glaser and Strauss stress the importance of generating conceptual categories only from the evidence inherent in the study sample, in order to develop a methodologically valid hypothesis.

2.2.6 Sorting

Concepts abstracted from the data and contained within memos written in the course of the study by the investigator were sorted in order to look for possible connections between the concepts that might help form the theoretical structure of the emergent

theory: indeed, whole new ideas emerged in the course of sorting. According to Glaser, the act of constant comparison, selective coding and sorting are the methods available to the investigator that can help pull together the evidence available in order to arrive at core categories, or the key themes that sum up identifiable patterns of behaviour or activity in the study.

2.2.7 Category development in this study

In the course of the study, the author selected and refined categories that best explained the research question under investigation. Eventually, 29 conceptual categories were identified that related to the core categories of patient knowledge-seeking and patient knowledge generation.

Following each interview, interview notes and any post-interview memos were re-examined for themes, facts and notable patient quotations. Comments not relevant to the study were eventually discarded. The remaining interview themes, facts and quotations were then compared to those of previous interviews to identify recurring topics, as well as topics that appeared to contradict previous interviews or subject areas that did not occur in previous interviews. Common and contradictory themes were used to enrich the emerging conceptual categories; new themes that emerged were also used to form the basis of new interview questions.

One example of how the constant comparative method was applied in this study was the development of the category 'patient knowledge may fail to determine action where the benefits of that action are deferred'. Three patients mentioned in different ways that they preferred an enjoyable life to a longer one devoid of pleasure – two patients in relation to alcohol intake and one in relation to taking HRT against her GP's recommendations, although these comments were not consistent with other health-related comments made by the same patients during their interviews. These opinions were described in an early category as 'patient preference for short-term pleasures over long-term survival', but the author was not satisfied that this adequately described what the patient had expressed in the context of their entire interview. Further interviews led to a refinement of the category, leading to a higher level, if rather wordy, emerging conceptual category, or theme: 'patients are self-critical about how short-term pleasures (such as eating and drinking) often override their ability to adhere to health advice'. The author encouraged patients to discuss their thoughts and feelings on health behaviours in more detail as the interviews progressed, as it seemed that further clarification might help explain what appeared an internal contradiction in patient interviews, whereby patients who reported high levels of adherence to the drugs prescribed and other medical advice also expressed a sense of personal failure and lack of willpower on other key health-related matters. When the contradictory themes around medical compliance and medical non-compliance were examined, a third theme started to emerge, 'health advice is less influential on long-term behaviours'. The author still felt this conceptual category was too general a statement that lacked a sense of the patient motive behind it. It was

when one patient explained that running for a bus was unwise and unnecessary as it might bring on an angina attack and another then discussed how you could never know really whether smoking had had a significant effect on your life span, as it was all statistics, that the category distinction between immediate and long-term health effects became more apparent. In a variety of different ways, patients had described experiences that expressed the fact that the connection between their health behaviours and their effect on that patient's mortality and morbidity was not directly measurable except in retrospect and often hard to prove. (The author also knew that such effects can only ever be predicted epidemiologically - at a population, rather than at an individual level.) Patient knowledge seemed to exercise significant influence over the management of behaviours which had immediate effects, such as learning not to behave in ways that might provoke an angina attack, or cancelling a dinner date if the interviewee started to feeling tired or unwell. However, patient knowledge seemed much less powerful when the effects of a health behaviour were postponed to an unknowable point in the future, such as when eating the wrong food, drinking alcohol or failing to take recommended exercise.

Patient comments continued to flesh out this category: by the end of the study, the conceptual category that bound all of the above observations together had become 'patient knowledge may fail to determine their health behaviours where the benefits of those behaviours manifest at an unknown point in the future'. The thesis found support in a US publication on healthcare innovation (Christensen et al, 2009), bolstering the author's estimation that such a conceptual category might form an

important hypothesis concerning patient management of long-term health maintenance and health behaviours.

3. METHOD

3.1 Study design and purpose

The study was set up to investigate patient knowledge and its role in the management of coronary heart disease, in response to predicted trends in health care and gaps identified in the existing literature. The study was organised around two research questions: firstly, what sources do CHD patients use when seeking knowledge about their condition and what are their reasons for doing so? Secondly, to what extent do patients, in the course of managing their CHD, generate knowledge about the condition and its treatment?

A qualitative patient study was set up and conducted over a 4-month period in 2009, consisting of face to face interviews with 34 patients with coronary heart disease who were being treated by GPs managed by Camden PCT. The study was conducted using grounded theory method. Additional information was sought from Camden GPs using an online questionnaire: 16 out of 34 GP surgeries in Camden PCT responded.

The author had initially planned to undertake a study that would involve patients who lived with a chronic disease. Patients specifically with coronary heart disease were chosen for study for three reasons: firstly, as CHD is the most prevalent disease in the

group of chronic diseases, CHD patients were likely to be in good supply in primary and secondary care; secondly, CHD is relatively easy to diagnose and has established treatment pathways, so there was unlikely to be a problem identifying correctly diagnosed patients; thirdly, as GPs are required to maintain separate registers of patients diagnosed with CHD, such patients should be administratively simple to invite to participate in a study.

3.2 Study setting

The study proposal was sent out to a number of Primary Care Trusts (PCTs) in London to identify where there might be local NHS management support for the study, as assistance from health professionals would be required for the recruitment of patients to the study. Following an expression of interest from Camden Primary Care Trust and subsequent discussions with key stakeholders, the investigator decided to base the study on patients selected through GP surgeries in the northern and central region of London covered by Camden PCT. Preliminary discussions were held with Camden PCT's Strategic Commissioner for Long-Term Conditions, the PCT's Project Managers for Self-Care and Tele-health, the London Regional Expert Patients Programme Lead, and the Regional Carers Primary Care Co-coordinator. All expressed an interest in enabling the research.

3.3 Study population

The Borough of Camden covers 22 square kilometres of inner city London. Its population is ethnically diverse: according to the 2001 census, 27% of Camden

residents are from black or minority ethnic groups, compared to an all-England average of 9%. A further 20% of Camden residents are white and non-British, a figure that includes Irish people and those from other English speaking countries, as well as from Eastern Europe.

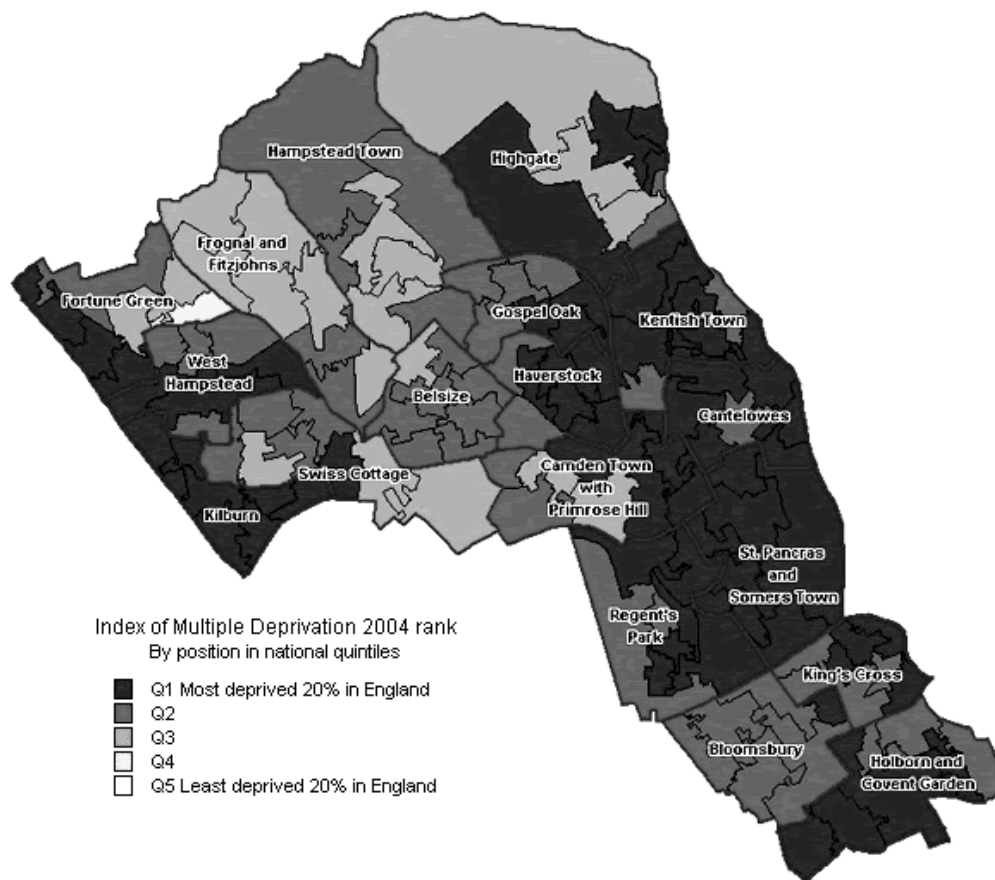


Figure 4.2 Borough of Camden: Index of Multiple Deprivation 2004

Source: Camden PCT

According to Camden Council data, every part of Camden has areas of relative affluence alongside areas of relative poverty. As a result, the Indices of Multiple Deprivation in 2007 ranked Camden among the 43 most deprived districts in England.

Health inequalities follow a familiar demographic pattern according to socio-economic status, gender, location and ethnicity: so, for example, men and women in the most deprived areas of the borough tend to live 9.9 and 7.5 years less respectively than those in the least deprived areas.

Camden has a higher proportion of people who describe their health as good when compared to the national population, and a smaller proportion of people over retirement age with a limiting long-term illness, due in part to being a university borough with a young student population. However, a larger proportion of working age people in Camden report having a limiting long-term illness compared to both the London and national averages, including coronary heart disease, which is of direct relevance to this study.

The patient sample in this study reflects this wide racial and socio-economic spread: even though a qualitative study such as this cannot make claims to be statistically representative of any given CHD population, some thought was given to recruiting a broad cross-section of patient types to try and make the study sensitive to issues that might be associated with to social or economic circumstances, even if this could only be hypothesised rather than proven.

3.4 Research Ethics Committee Approvals

The project was approved by the Cranfield University Research Ethics Committee in

November 2008. The relevant documents were then submitted to Camden and Islington Community NHS Research Ethics Committee and approved in January 2009.

The main ethical issues identified were ensuring informed patient consent, patient safety and patient confidentiality for those patients opting into the study. To ensure that patients understood what they were consenting to if they chose to take part, consent forms and patient information sheets were developed for both patients and their carers where appropriate (appendices C and E). The information sheets explained the aims of the study and what was being asked of the patient, and stated clearly that participation in the study would not affect the patient's medical care in any way. Patients were only asked to sign consent forms once they had met with the investigator, read and understood the information sheet, had an opportunity to ask any additional questions and had taken part in the interview.

Patient safety was also considered in advance: on the advice of Camden PCT's ethics committee, the investigator carried contact details for each interviewee's GP in case a patient became very distressed or in need of medical treatment whilst being interviewed. In the event, this did not prove to be necessary. Patients were also encouraged to have a friend or family member attend the interview if they thought they might require any kind of practical or emotional support. No interviewees chose to take up this option, with the exception of one interviewee who required a carer to be present due to the severity of their condition.

In order to protect patient confidentiality, GP surgeries had to handle the initial request for patient volunteers for the study. Following interview, it was agreed that all patient-related data would be anonymised, published in an anonymised form and stored in a password-protected computer hard drive. All documentation such as the signed released forms and patient names and addresses are stored in a lockable cupboard and will be destroyed securely by the investigator in 2013.

Once Camden REC approval was given, an honorary contract of employment was issued by Camden PCT to the investigator, who was also required to register with the PCT's Occupational Health team and undergo a Criminal Records Bureau check prior to the commencement of the study.

3.5 Recruitment of participants

A method of inviting relevant patients with CHD to participate was agreed with Camden PCT and participating GPs: patients would be contacted using the CHD register held by most GP practices. CHD registers were set up in most GP surgeries following recommendations in the NHS National Standard Framework for coronary heart disease in 2000 and the General Medical Services Framework in 2003. Both documents stated that general practitioners and primary care teams should develop a register for CHD patients aged between 35 and 74 years of age to ensure that they could be monitored and targeted in order to reduce their risk of acute episodes and improve their health status. The NHS Quality and Outcomes Framework for CHD states that such registers

‘... will include all patients who have had coronary artery revascularisation procedures such as coronary artery bypass grafting (CABG). ... Practices should record those with a past history of myocardial infarction as well as those with a history of CHD.’

3.5.1 GP surgeries

The investigator had specified to Camden REC that up to 40 male and female patients would be selected for interview: the number was selected as an indication of the maximum number of patients the investigator thought might be necessary, having taken advice from other, more seasoned qualitative researchers.

Every GP practice manager in Camden PCT was contacted by phone and email and asked if their practice would consider participating in the study: a copy of the study protocol accompanied each request (appendix F). There were a number of practical problems uncovered that prolonged this first-stage contact: information regarding practice managers and their contact details provided by Camden PCT was out of date and inaccurate; when correct names and numbers were arrived at, many practice managers simply failed to respond to phone calls and emails.

Some GP practice managers who responded felt unable to take part: some cited pressure of routine work as the reason they could not consider participation in the study; others reported that they had passed information on to relevant GPs in the practice but had not heard back from them and had no time to chase a response; some practices were already taking part in studies and felt they could not commit to

another. After three weeks of follow-up, six GP surgeries and Camden's Expert Patient Programme had expressed a willingness to take part in the study.

Following a further two weeks of organisational discussion with the staff involved, one GP Practice Manager felt unable to participate due to staffing problems; another surgery did not in fact hold a separate register of patients with CHD; the Expert Patient Programme dropped out due to there being no record of patients with CHD having participated or currently participating in their courses around the time of the study. Four GP surgeries in Camden were finally eligible and willing to participate in the study. As part of the agreement that seeks to safeguard patient confidentiality, the participating surgeries will not be named in this study: however, it is worth noting that the surgeries involved were fortuitously situated in different parts of the borough of Camden and between them treated patients from a wide range of socio-economic and ethnic backgrounds.

3.5.2 Patient Selection: inclusion criteria

The study protocol, as agreed by the local NHS Research Ethics Committee, specified that participating patients should have been diagnosed with CHD: patients were defined as such on the basis of the pre-existing medical diagnosis which had led to the patients in question being placed on the GP practice register of patients with coronary heart disease. The patient's self-reported health status was also checked at the start of each interview to ensure that each interviewee was able to recount a medical

history and a medication and treatment regime typical of a patient with coronary heart disease.

Patients were also required to be able to speak passable English due to the non-availability of interpreters throughout the study period. They were required to be 30 years of age or over, as chronic disease typically occurs in late middle-age; they also had to be judged by their GP to be physically and mentally capable of giving informed consent (appendix F). Patients were excluded if they were considered by either their clinician or the author/investigator to be too unwell to take part in an hour-long interview.

3.5.3 The patient invitation process

Due to the requirements of patient confidentiality, participating GP surgeries sent out the initial letters of invitation and study literature to all the patients on their CHD registers (appendices B and C): the investigator then received contact details directly from those patients who expressed an interest in taking part (appendix D).

75 letters to patients were mailed out in total from GP surgeries: 61 letters of response were received by the investigator. Of these, 11 patients replied that they did not wish to participate. 50 patients were judged eligible for inclusion in the study on the basis of their reply letters. Of these, 34 were visited and interviewed until the investigator decided that the categories of information being studied were adequately covered, or 'saturated'.

3.6 Patient sampling

In line with theoretical sampling methods, the author aimed to generate a patient sample, selected throughout the study period, with sufficient diversity to illuminate a wide range of patient response to the relevant study questions, and provide a exploration in some depth of any theoretical direction that emerged during the course of the study. It is perhaps worth reminding the reader that a qualitative study of this kind cannot reach statistically significant responses to any study question, nor is it able to state that the *incidence* of CHD patient experience and views recounted in the patient study are representative of the incidence of such views and events in the CHD patient population as a whole. The aim is rather to generate hypotheses and theoretical frameworks relevant to patient knowledge and chronic disease management: such theoretical frameworks can indicate fruitful areas of research and practical social experiment, and also help provide direction for future quantitative analysis.

In line with theoretical sampling methods described in section 2.2.1 earlier in this chapter, the author sought out patients according to different criteria at three key stages in the interview process. Firstly, the need to locate female CHD patients became apparent, in order to explore the noted gender differences concerning information seeking and retrieval mentioned in the literature, as very few women were available in the pool of patients who had volunteered to take part in the study. Secondly, there was later also a perceived need to interview younger CHD patients to

investigate how age and economic activity appeared to influence patient views concerning internet knowledge-seeking and attitudes to knowledge management interventions. Thirdly, the investigator also tracked down CHD patients who had *not* undergone a serious health event such as a heart or angina attack, in order to investigate how knowledge seeking and knowledge generation might be influenced by degree of illness in the cohort of patients interviewed.

3.7 Data collection

Data collection involved 2 elements: firstly, semi-structured interviews were conducted face-to-face with CHD patients; secondly, a supplementary online questionnaire was devised and distributed to each GP surgery in Camden to provide a GP perspective, where relevant, on themes that had emerged in the course of the patient interviews.

3.7.1 The patient interviews

34 patient interviews were conducted between 8th May and 23rd August 2009; the duration of interviews varied between 45 and 90 minutes, depending on how much each interviewee wished to say. Individual face-to-face interviews enabled the investigator to spend some time putting patient interviewees at their ease prior to the interview taking place; it also allowed the investigator to observe patient behaviour and non-verbal cues in the course of the interview in order to help assess the extent to which each interviewee felt able to be open and honest. Some questions were put

more than once in slightly different ways to check the patient's response. Supplementary questions were used to probe unclear responses unless it was clear that the patient did not wish to be probed further.

The investigator accompanied 2 patients on a visit to their GP and hospital consultant respectively, to observe interaction with medical staff and the exchange of knowledge and information during a consultation. However, this practice was discontinued when it became clear that the presence of the author proved too intrusive to allow proper observation to take place.

Patients were given the option of being interviewed in an office in the PCT building on Camden Road, in a quiet space in public such as a cafe, or in their own homes. 30 out of 34 patients chose to be interviewed in their homes, three chose to be interviewed in the quiet corner of a cafe and one person chose to be interviewed in his workplace. The home interviews were the most productive, in terms of the degree of patient time available and the additional ease patients appeared to enjoy by being in their own home surroundings: conversation flowed more easily and patients were generally open and reflective. Socio-economic context and overall living circumstances were generally easier to gauge by talking to patients in their homes, where they were surrounded by the objects and photographs of people who mattered to them. Interviews were simultaneously recorded by hand. Only one interviewee became upset and tearful in

the course of being interviewed, but had recovered by the time the interview had finished and was happy to sign the consent form.

The activity of comparing interviews to look for emerging themes was conducted after each interview: a stage was reached where successive interviews failed to develop significant new insights into existing categories or suggest new categories: the study was halted after 34 patient interviews had been completed.

3.7.2 Coding, memos, sorting and development of core categories

Interview notes were coded by theme; memos noted emergent themes, investigator observations and any links or contradictions immediately noticed between patient interviews. Throughout the patient interview period, the interview codes were grouped and themed. The frequency of coded themes in patient interviews was noted, as were any apparent contradictions or unusual patient responses.

The move to conceptualise the categories came at a late stage in the study, when it became clear to the investigator that the frequency of particular patient answers was insufficient in itself to describe what the responses signified. So, for example, the fact that so many patients in their interviews described how they sought information about CHD from close friends and family might seem irrational, given that few if any friends and family members were qualified to give advice on such matters. It was only once

the *nature* of the knowledge sought was examined by the author/investigator that it became possible to conceptualise the meaning behind such patient actions.

It became clear that knowledge-seeking among the patients interviewed was determined by more than a search for an objective, scientific proof: in fact, they appeared to seek out a range of quite different types of knowledge from different sources. This realisation served to enrich the descriptive categories, such as 'doctor', 'nurse' and 'family' knowledge sources used by patients, by using more conceptual categories, such as 'expert', 'practical' and 'folk' knowledge that better explained the nature of the value of the knowledge source to the patient. This result is set out in detail in chapter 6.

One key theme that emerged late in the study, as the author tried to encapsulate an identifiable pattern of activity was that 'patient acts of knowledge creation are often unrecognisable in their initial form'. The act of conducting the study itself became part of a knowledge creation process, so that it was possible to say that 'patient acts of knowledge creation often need to undergo knowledge conversion in order to be of organisational value'. This result is set out in detail in chapter 7.

3.8 The GP Questionnaire

An online questionnaire for GPs was developed in the course of the patient study for two reasons: to provide summary information on formal GP practice behaviour

regarding the exchange of knowledge and information with patients; and to follow up some of the matters raised by CHD patients in the course of the interviews that reflected directly on GP practice.

The author took into account that GPs were likely to cite lack of time as a reason for being unable to respond to any request for information. These considerations prompted the development of a brief questionnaire that could be filled in in less than 15 minutes and returned online or by post (appendix G). The questions were devised to enable the GP to select an answer where possible from a list of options by a click of the mouse. Other questions left blank answer boxes about 3 lines long for the GP to fill in, rather than providing large blank spaces that might give the impression that long and time-consuming answers were required. The GP participants were informed that their responses would be anonymised prior to use in any publication. A copy of the questionnaire was sent to each surgery practice manager in the borough of Camden, where the patient study was conducted: after considerable follow-up effort, 16 out of 43 GP practices completed and returned the questionnaire.

4 VALIDITY

4.1 Measures of validity in grounded theory research

Grounded theory does not seek to report statistically significant probabilities, but rather conceptual hypotheses grounded in empirical data (Glaser, 1998). Validity as it is traditionally understood is not used to measure the truthfulness or accuracy of study

results. So, for example, replicability is not regarded as a good measure of validity in grounded theory, as it is understood that the individual interviewer is not a replicable measuring instrument, may elicit responses not available to another interviewer and does not adhere to a predetermined set of questions. In order to be valid, grounded theory analysis must be true to the data collected, as validity is considered inherent in the data gathered, rather than independently verifiable: results generated in the process of analysis are considered to be validated through the process of constant comparison and category saturation.

Glaser states that valid grounded theory research should satisfy six criteria: it should have 'fit', in that the categories developed must be applicable to and indicated by the data, rather than developed outside of data analysis. It should 'work', in that it should be able to explain the behaviour under study in a plausible way. It should be 'relevant to the subject and people under investigation', in that the outcomes should reflect the concerns expressed by the study participants. It should be 'modifiable', that is, open to development when brought into contact with relevant new data. It should be 'parsimonious': in other words, any theorising should seek the simplest means to any given end. Finally, it should 'demonstrate scope in its explanatory power', meaning that findings should relate meaningfully to each other and related material external to the study (Glaser, 1978; Glaser 1998).

Triangulation can be used to assist with validation, in that previous work in the field

can be used to sensitise the investigator, but Glaser and Strauss are adamant that previous work should not close the mind of the investigator to other possible outcomes and explanations than those previously established elsewhere. They even state that an analyst should enter the field without any prior knowledge of pre-existing relevant theoretical work in order not to be swayed by theories generated outside the actual study data. However, this precept was rejected for the purposes of this study, where both time constraints and intellectual rigour demanded a higher degree of familiarity with the topic under investigation than this approach would have allowed.

The warning from Glaser and Strauss to be wary of the seductive effect of past and prevailing understanding on new ideas is well argued, but probably overstates the extent to which anyone can arrive at a subject untouched by prevailing ideas. Furthermore, it is doubtful that the process of developing theory in this context is best served by ignoring other views and perspectives. Nevertheless, it was useful to be reminded of the importance of maintaining a discreet distance from pre-existing theoretical assumptions in the course of research and ongoing data analysis.

4.2 Investigator bias

The investigator is also the measuring instrument. Interviewer bias on the part of the investigator is always a possibility, so particular attention was paid to question formulation, interviewer response and external monitoring of the interviewer's work. Great care was taken to ask open questions that did not indicate a desired answer

from the patient. Time was taken to allow sufficient time after a question was asked to allow more hesitant respondents the opportunity to think and answer. Patient replies were treated evenly, particularly when a reply contained an opinion that the investigator disagreed with. In terms of external monitoring, ongoing support was sought from a number of experienced researchers and interviewers throughout the study to monitor and discuss progress, including the possible problem of bias arising from the study process. The investigator/author also benefitted from a prior professional background as a television journalist and programme producer, trained in non-biased interview technique, who practised these skills extensively as a television producer and later as a hospital project manager.

4.3 Self-reported data and recall bias

Patient self-reported data relies on each patient to be honest, accurate and able to remember events, some of which may have taken place a long time in the past. Chan (2009) states that, although there is cause for believing that desire for social acceptability or investigator approval may indeed cause respondents to lie or exaggerate when providing data, this cannot be the case for all data, with gender and ethnicity being the most obvious examples. He also points out that falsifying answers seems to be more of a problem for experimental studies than measures used in field studies and naturalistic settings. Furthermore, a study by Khoury et al (1994) concludes that the effect of recall bias is often overrated. Many studies have shown that self-reported data regarding data such as height and weight correlates highly with

measured data (Niedhammer et al, 2000; Spencer et al, 2002), although it is also noted that there tends to be a systematic bias in such data, with height generally overestimated and weight underestimated (Gorber et al, 2007).

This study relies heavily on self-reported patient data – with important exceptions: expert medical opinion is responsible for the medical diagnosis and treatment regimen, prescription medication was checked and discussed by the investigator when visiting patients in their homes. Observation enabled the investigator to make her own visual assessment of such matters as the extent to which a patient was overweight.

Patient statements regarding adherence to taking prescription medication as recommended were not independently verified, as any such tests would have been intrusive, costly and disproportionate to their importance to the study. As the patient group was generally highly motivated, any lapse in taking medication was discussed quite earnestly and none of the patients interviewed showed signs of being evasive when questioned on such matters.

A patient's recall of what a doctor or nurse said to them at some stage over the course of their treatment was unverifiable: no doctor is likely to remember a conversation with a patient as vividly as the patient may be able to recall it. However, one can also assume some degree of memory lapse or lack of ability to recall in detail everything that is said in a consulting room on the part of a patient, or partiality in the reportage,

especially with events that may have happened years ago. What such recalled incidents best measured was not the specific detail of an event, but the emotional trace left behind on the patient, and it is in that spirit that patient statements concerning their healthcare and their experience of health professionals are reported.

4.4 Selection bias

Selection bias tends to favour some and deter other participants from taking part in a study and thus distort its findings. Grounded theory replaces representative sampling with theoretical sampling: the investigator can sample interviewees in order to investigate emerging conceptual categories rather than adhere to a pre-determined sampling framework. However, it is still important to consider which patient types may have been excluded from the available pool of patients *prior* to the author's patient selection.

In order to gain research ethics committee approval, patients were required to opt into the study by return letter sent by their GP practice prior to meeting the investigator. The letter was also required to contain a detailed information leaflet. The act of opting into such a study creates an inherent problem of self-selection bias, favouring those patients who are most motivated to join a study, for reasons of availability, interest or goodwill. It is also likely to deter those who feel they are too busy or unable to read the written material, sign a form and send it back in an envelope. Studies confirm that the requirement for health researchers to obtain

written informed patient consent itself causes significant selection bias, with statistically significant differences between study participants and non-participants in terms age, sex, race, education, income and health status (Kho et al,2009; Woolf et al, 2000). The effects of this form of selection on the study results will be considered further in the limitations section in chapter 9.

5. STUDY SCHEDULE

Study preliminaries, including the preparation of the application for the research ethics committees, enrolment of the participating GP surgeries and the sending out of patient invitations, to the start of the interview process, lasted 6 months, from November 2008 to May 2009. The set up and completion of patient interviews and the preparation, dispatch and receipt of GP questionnaires lasted a further 5 months, from May until October 2009.

The study schedule was prepared according to the plan in Table 4.1 below. In practice, many phases of the work stages set out above overlapped in practice. There was no rigid separation between the pilot and actual interview stages, as grounded theory research allows for interview questions to change and develop over the period of the study as core categories emerge.

Questions were piloted initially by interviewing two patients and reviewing the results:

clumsy interview questions were revised as a result and further questions were prepared to follow up sometimes brief answers on patient knowledge-seeking.

Patient Case Studies Pilot interviews			Patient Case Studies Interviews	
Literature Review	Analysis of existing literature			
Preparation of case Studies	Interview guidelines	Draw up i'view themes	Interview guidelines	Ongoing revision of I'veiw themes
Data collection	Conduct 2-3 interviews	Data coding & analysis	Conduct remaining Interviews	Data coding & analysis
Observation	Patient observation: examine tacit learning		Patient observation: examine tacit learning	
Data analysis	Analyse collected data	Revise questions	Analyse collected data	Theory development

Table 4.1 Study schedule

It also became clear that interview time would have to allow for the fact that patients seemed to need about 10 minutes at the start of each interview to describe their illness and key acute events: even after some years, patients still clearly felt the trauma and accompanying need to explain what had happened to them.

CHAPTER 5 | PROFILE OF THE PATIENT COHORT

1. INTRODUCTION

This chapter provides a profile of the patient cohort interviewed. It considers their gender, age, educational attainment, socio-economic status, ethnicity, length of time since diagnosis, severity of condition, the presence of other chronic conditions, medication regime and domestic circumstances. All of the above characteristics were considered during patient selection at different stages of the interview period, as the author anticipated that they might exercise some effect on patient knowledge-seeking and knowledge generation.

Graphs are used where it is useful to provide an easy visual summary of the distribution of patients in profile categories.

2. THE PATIENT COHORT PROFILE

An anonymised list of patients, accompanied by basic demographic details, is set out in appendix A.

2.1 Gender

34 patients were interviewed: 26 men and 8 women. The number of men in the sample reflects the much greater number of men who agreed to be included in the

study; this in turn reflects the relatively large proportion of men on CHD registers, as men have a greater risk of heart attack than women and tend to experience heart attacks 10-15 years earlier than women (Gilbert, 2000). Women are also less likely than men to receive a preliminary diagnosis of heart disease when they present with chest pain, and are less likely to be referred for further investigation (Richards et al, 2000).

The smaller number of women available to the study made any possible gender-related differences in response less easy to detect. The range of responses of the 8 women in the study did not seem discernibly different when compared to the range of male responses, with one exception: a greater proportion of the female patients commented positively on the high value they placed on advice and support from other patients, but this was by no means common to all 8 women.

2.2 Age range

Patient ages ranged towards the older end of the population, which is unsurprising, given that the effects of chronic disease tend to manifest in middle to old age (figure 5.1). The existence of multiple chronic conditions also increased with patient age.

Patient age was anticipated to be a factor in patient attitudes to the internet, as well as accounting for internet searches by proxy, as older people tended to be less familiar

with computer-based work. This is likely to be a generation-specific, rather than a permanent age effect.

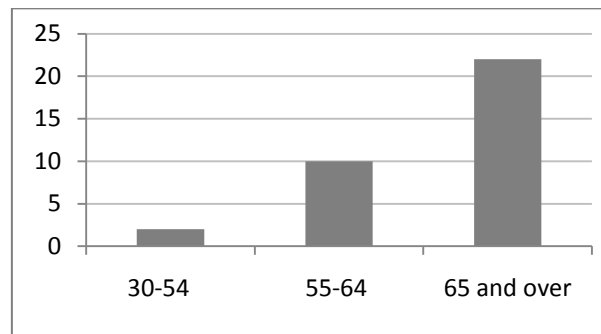


Figure 5.1 Patient cohort: age distribution

2.3 Educational attainment

There was a broad spread of educational attainment amongst patients interviewed: it was interesting to note that 44% of the cohort was highly qualified with a university degree or higher, even though poor health is strongly associated with lower educational attainment (Sundquist et al, 2007). There are a number of possible reasons for this.

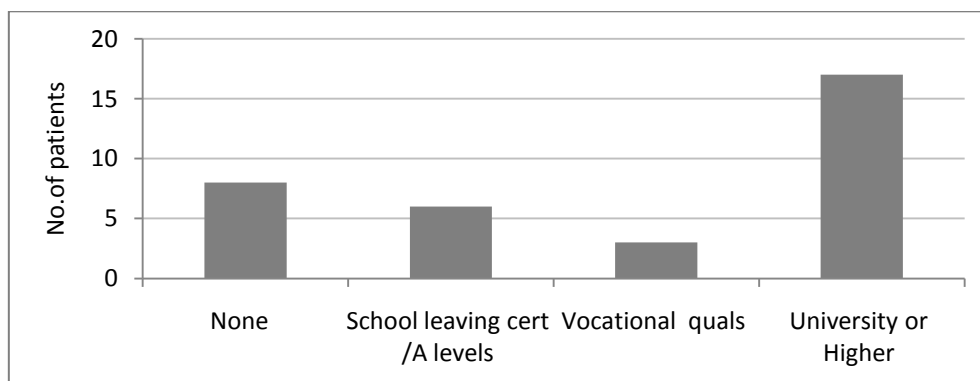


Figure 5.1 Patient cohort: educational attainment

It may be due to self-selection: highly educated patients may be more willing or able to take the time to participate in a voluntary patient study; alternatively, more highly educated patients may end up on the CHD register in larger numbers due to better GP attendance or differential treatment. Educational attainment, along with socio-economic status, did appear to have an effect on patient trust and knowledge-seeking, and is discussed in chapter 6.

2.4 Socio-economic status

The patient cohort contained a broad spread of social class, as defined by the patient's current employment or by a patient's previous primary employment if retired. This was assessed using the National Statistics Socio-Economic Classification (NS-SEC), the most current method of defining socio-economic status.

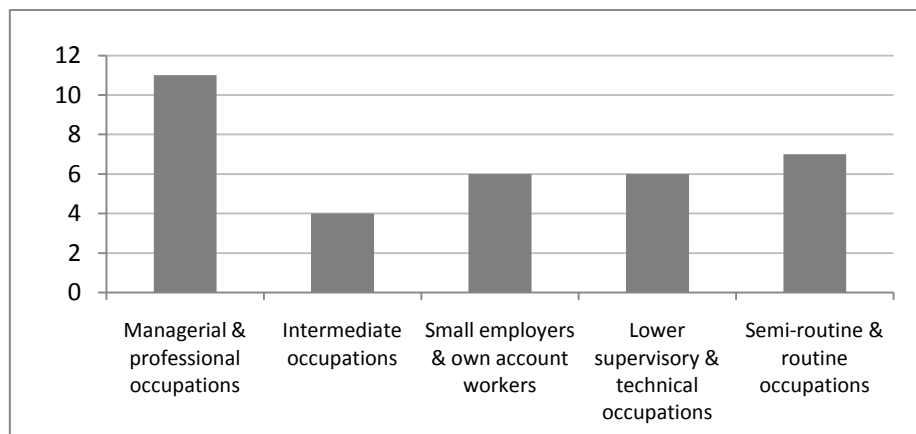


Figure 5.2 Patient cohort: socio-economic status (NS-SEC)

Along with education, socio-economic status appeared to account for the differential

impact of patient trust on knowledge-seeking behaviour. It also enabled some of the wealthier patients to seek the medical opinion of private consultants.

2.5 Ethnicity

The patient cohort contained a broad spread of ethnicity, characteristic of an inner London Borough.

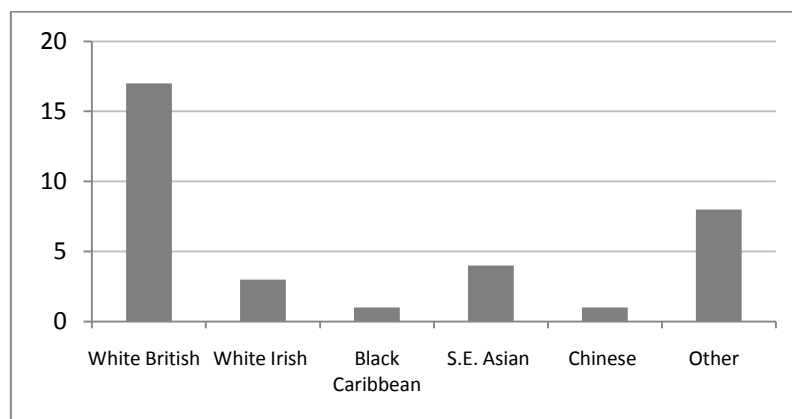


Figure 5.3 Patient cohort: self-reported ethnicity

The 'other' category, encompassed patients originally from Australia, Switzerland, South Africa, Greek Cyprus, Canada, Egypt, Germany and New Zealand.

A higher proportion of south-east Asian patients might have been expected to respond to the study, given the raised frequency of coronary heart disease among people of south-east Asian descent relative to their white counterparts. There are a number of possible reasons why people of south-east Asian descent were not available to the study: some patients with poor English language skills were excluded from the study due to non-availability of translators during the study period. It is also possible that

south-east Asians may be under-represented on the CHD registers relative to the statistical incidence of CHD among Asians; they may have been less willing to take part in a voluntary study, or, where English was a second language, Asians with English as a second language may have been less willing to respond to the invitation written only in English. As a result of the exclusion criteria, poor English skills did not feature strongly among non-English patients in the study: people with poor verbal English were screened out of the study, due to non-availability of translators. Ethnicity per se did not appear to make any impact on patient knowledge-seeking or knowledge-generation, although English as a second language meant that two patients preferred not to read health literature written in English.

2.6 Length of time since initial CHD diagnosis

The study was deliberately skewed towards patients who had lived with their chronic condition for 12 months or more, as this enabled the author to investigate how patients manage their condition in the longer term, as opposed to immediately following diagnosis (figure 5.5).

It was noticeable that recently diagnosed patients tended to be more bewildered by the aftermath of an acute event such as a heart attack and were less familiar with the clinical pathways and treatment issues that became more evident to patients over time.

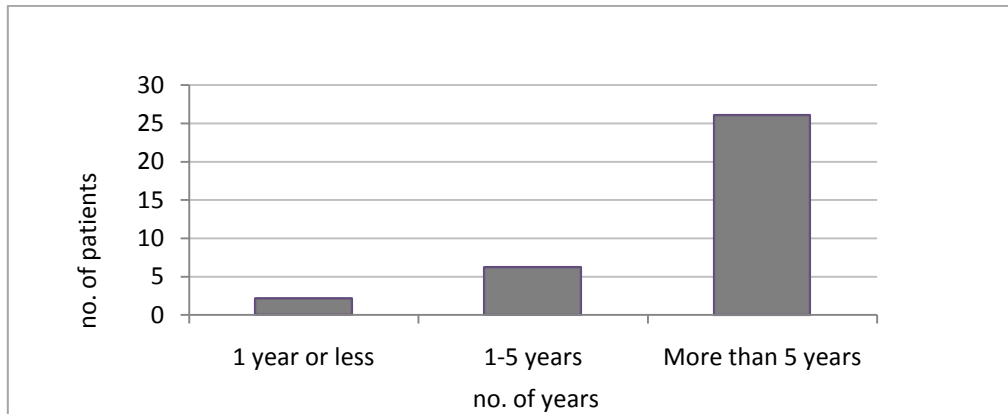


Figure 5.5 Patient cohort: length of time since CHD diagnosis

In the immediate aftermath following diagnosis, patients may change their patterns of health behaviours in ways they find unsustainable in the longer term: it is the longer term consequences of managing a chronic condition that are often outside the time span examined in patient studies and that were of interest in this study.

2.7 Severity of condition

In terms of cardiac events, 13 patients had suffered one or more heart attacks, 3 had had one or more strokes, 10 patients suffered from acute angina and 4 suffered from the effects of heart failure. Some patients selected for the study had much milder manifestations of CHD: 4 patients were taking medication for diagnosed high blood pressure and had not suffered any kind of acute health event. The author was curious to see whether patients with lesser symptoms showed the same kind of knowledge-seeking behaviours as patients with more advanced CHD. In fact, knowledge-seeking behaviour appeared to be less influenced by the severity of the patient's condition than by other characteristics, such as patient trust in medical experts. This will be discussed in more detail in the results in chapter 6.

2.8 Multiple conditions

28 out of 34 patients who had CHD reported receiving treatment for one or more additional chronic diseases, including hypercholesterolemia, diabetes, COPD, prostate cancer, arthritis and Lupus. The co-existence of multiple chronic conditions tends to increase with age and is much under-reported in patient studies (Smith et al, 2007).

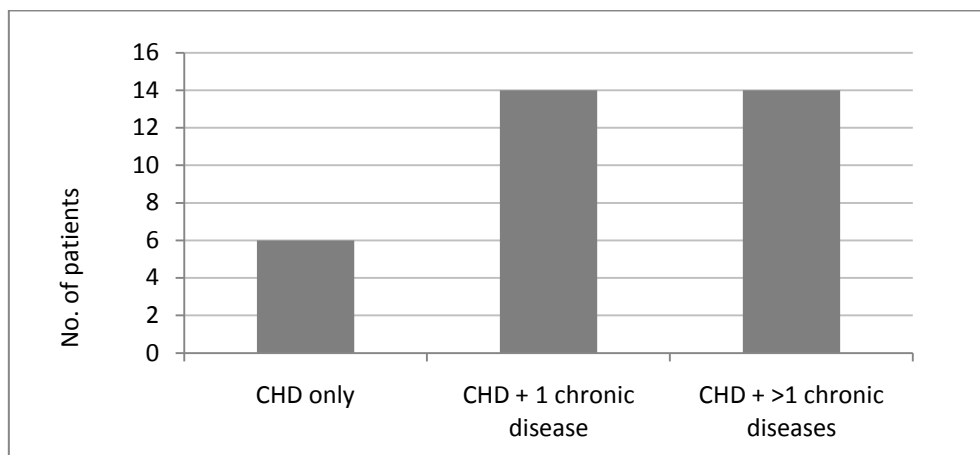


Figure 5.6 Patients with multiple chronic conditions

Living with multiple conditions often requires a complex of treatments across a range of clinical specialities: as such, it tends to add to the complexity of patient self-care and increase their interaction with health professionals, which itself may have an effect on patient trust and knowledge-seeking.

2.9 Medication

For all the patients interviewed, a daily prescription medication regime was a key factor in managing their conditions: most patients were taking a large number of pills every day.

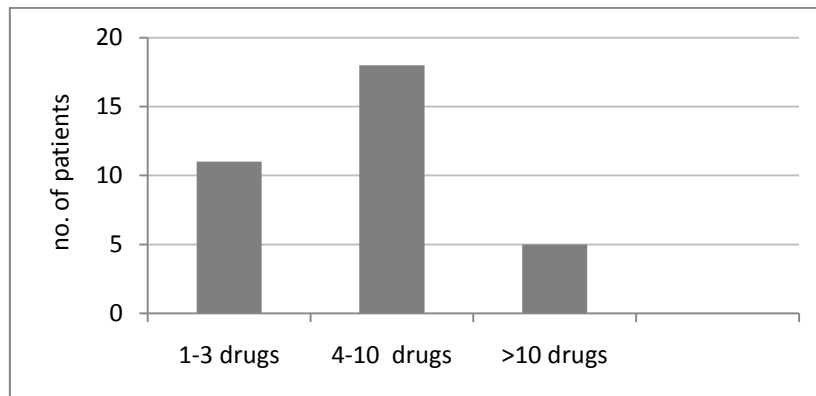


Figure 5.7 Patient cohort: prescription medication taken daily

The graph above identifies the number of different types of medication taken by each patient on a daily basis and excludes any additional self-medication by the patient, in the form of supplements or ‘alternative’ medicines or treatments. The amount of daily prescription medication was considered possibly significant to the patient study by the author, as the experience of side effects is likely to increase as the number of daily medications taken increases – this may affect patient adherence to medication, which is clearly more onerous for a patient taking 10 or more drugs every day. The fact that patient adherence was self-reported as very high indicated a higher degree of self motivation among patients in the study than was reported to be the case in the patient population in general. This is discussed further in chapter 6.

2.10 Domestic Circumstances

16 patients lived with a spouse or family member who was also able to care for them when required: 7 of these people were both themselves patients with CHD as well as primary carers for a spouse with a long-term condition.

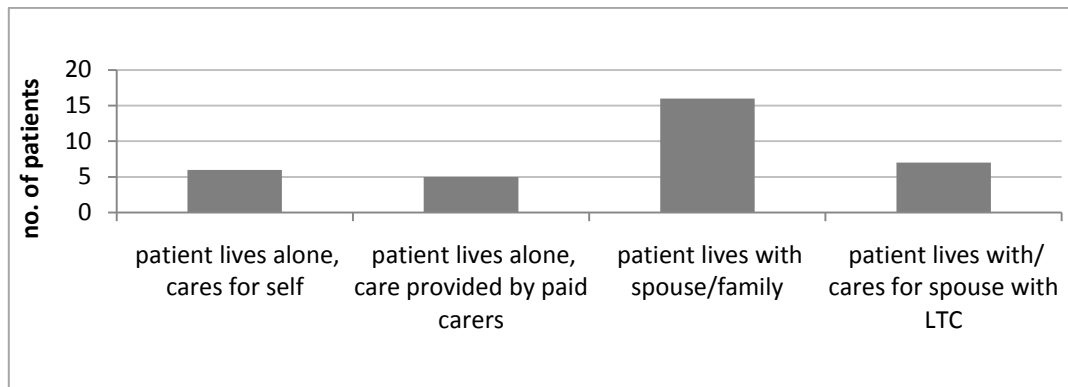


Figure 5.8 Patient cohort: domestic circumstances

11 interviewees lived alone: of these, 5 patients received home support from private or public sector care workers. This was considered by the author to be a potentially significant criterion for selection to the study in terms of examining how co-habitation with others might affect knowledge-seeking, compared to those who lived alone. The experience and attitudes of the study patients suggested that co-habitation was less significant than the degree of patient social support generally, irrespective of whether the patient lived alone.

2.11 Patient understanding of the causes of CHD and associated risk factors

Patients were asked to explain their medical condition and the risk factors they attributed to their own condition. All patients were able to explain in layperson's terms a retrospective understanding of the signs and symptoms of their heart condition and what they thought had caused it; where relevant, they were able to explain surgical interventions such as an angioplasty, an angiogram or stents; all had a good understanding of the changes in lifestyle and health behaviours associated with

effective long-term health maintenance and secondary CHD prevention as recommended by NICE. This finding was not directly relevant to the study questions, but was an important preliminary question that served to rule out any likelihood that patient health behaviours considered later in the study might be the consequence of a lack of patient knowledge or understanding about their condition and its associated risk factors.

Most interviewees were able to explain what had happened to them and why in considerable detail and showed a good comprehension of the medical interventions they had undergone. 4 out of the 34 interviewees showed less evidence of a lay understanding of the function and purpose of the medication they took on a daily basis to control such conditions as high blood pressure , cholesterol levels or angina.

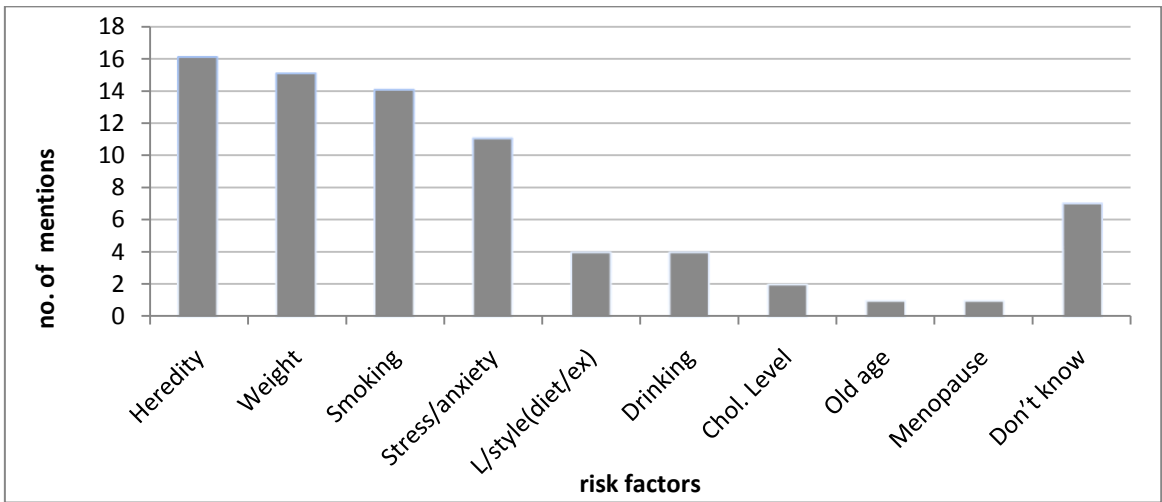


Figure 5.9 Risk factors to which patients attributed their CHD

When discussing what they thought had caused them to contract coronary heart

disease, the reasons given by patients were all medically recognised risk factors for CHD (figure 5.9).

Inherited genetic propensity to CHD was mentioned most often as a major cause, but patients also readily attributed their CHD to lifestyle-related risk factors, such as excess body weight, smoking, unhealthy diet, drinking too much alcohol and stress.

These findings are supported by previous studies that report a good understanding of CHD risk factors in the population at large and across all socio-economic groups (Davison et al, 1991; Gabhainn et al, 1999). The findings suggests that any patient behaviour that deviates from what is recommended by medical experts, as will be reported in chapter 7, is not likely to be the result of ignorance of the facts.

3. SUMMARY

People included in the patient study exhibited many of the features common to people with varying degrees of CHD, in terms of their age range, existence of multiple conditions and amount of daily medication prescribed. Only education, socio-economic status and, to a lesser extent, gender and social support, appeared to make an impact on patient knowledge-seeking behaviour and subsequent actions. Such numerically-based observations are advanced tentatively here, but provide some basis for hypotheses that would require quantitative research in order to substantiate their true effect in the broader patient population.

Other, more abstract and conceptual patient characteristics that appeared to influence patient knowledge-seeking and knowledge-generation emerged in the course of the interviews. These are reported in the results chapters 6 and 7.

6 | RESULTS (1): WHAT SOURCES DO PATIENTS USE WHEN SEEKING KNOWLEDGE ABOUT THEIR CONDITION, AND WHAT ARE THEIR REASONS FOR DOING SO?

1. INTRODUCTION

This chapter sets out and analyses the content of the patient interviews that relates to the research question ‘What sources do patients use when seeking knowledge about their condition, and what are their reasons for doing so?’. Following data reduction to exclude subject areas irrelevant to the study question, 8 results were identified, and are reported below. Each category is examined analytically. The chapter concludes with a summary of the results.

2. DEVELOPMENT OF CATEGORIES

The task of arriving at the categories set out below involved analysing the data contained in patient interviews, moving away from description towards the generation of conceptual categories grounded in that data. Patient interview data was first reduced to exclude any data that did not relate either directly or indirectly to the first study question.

Data was abstracted and analysed: 28 descriptive categories were analysed and merged into 8 categories in order to construct a more conceptual and rounded understanding of patient knowledge-seeking. Some of the descriptive categories were the direct result of questions put by the investigator to the interviewees, such as the discussion of patients' understanding of CHD and the associated risk factors, and patient opinions on accessing NHS-held patient data. Other categories emerged from the data at a more abstract level, such as the findings on the types of knowledge sought by patients, and the findings on the relationship between patient trust of their GP and knowledge-seeking. All categories were based on data in the patient interviews: by way of additional validation, the findings were (a) compared and contrasted with findings in the existing literature and (b) discussed with academic colleagues.

Graphs are used where relevant to show the reader the range and distribution of patient responses. These graphs relate only to the patient sample interviewed and of course should not be taken to indicate the prevalence of particular opinions in the CHD patient population as a whole.

3. RESULTS

3.1 Patients seek different types of knowledge from different sources

The patterns of knowledge-seeking behaviour described by patients suggested that different types of knowledge were sought from different sources, often at different stages of the chronic illness trajectory.

When discussing who or what they turned to when seeking medical advice, the five most commonly cited sources by patients were their GP or GP practice; their hospital doctor(s); close friends and family; nurse specialists and cardiac trainers; and the internet. These responses were broadly in line with the findings of previous studies into knowledge-seeking behaviour mentioned in Chapter3 (Munro et al, 2000; Mori, 2003; Coulter et al, 2005).

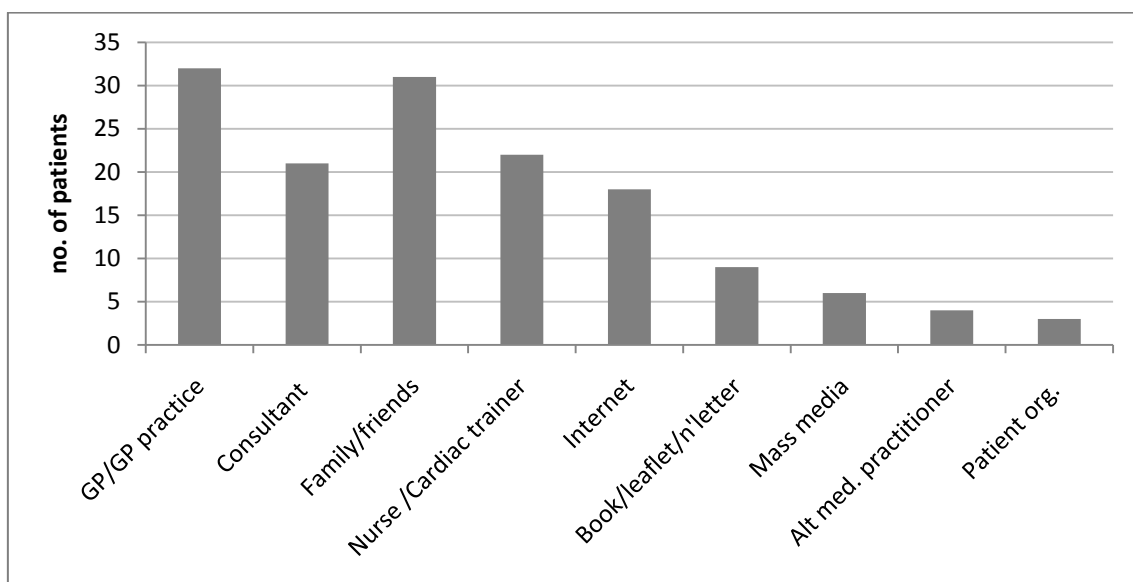


Figure 6.1 Patient self-reported sources of medical knowledge and advice

Cardiac trainer is a category of healthcare expert that emerged as a result of 14 patients having attended cardiac rehabilitation programmes following a heart attack and their subsequent release from hospital. Patients distinguished quite clearly between different professional knowledge sources without prompting.

With the exception of studies into patient knowledge-seeking on the internet, previous research into patient knowledge-seeking behaviour was largely quantitative, and could only report what proportion of patients appeared to use which knowledge sources. This study was able to investigate the reasons *why* patients used a range of different knowledge and information sources: was it simply random behaviour, based on who was most accessible to the patient at the time they wished to know something about their condition? If there was more purpose than this behind the patient's selection of a knowledge source, then what motivated that choice?

A second point of enquiry was to find out what *kind* of knowledge was being sought? The author encouraged patients to discuss both these matters. Subsequent data analysis showed common patterns of knowledge-seeking behaviour among the patients interviewed, both in terms of the different types of knowledge sought and the knowledge sources associated with that type of knowledge.

3.1.1 Expert knowledge-seeking: GPs and hospital consultants

It was not surprising that patients mentioned their GP or GP practice, and their hospital doctor(s), as important and valued sources of health knowledge and advice. It

emerged, however, that GPs and consultants were valued by patients specifically for their *expert biomedical knowledge* about the patient's condition. Patient examples of this type of knowledge included expert opinion about selecting the right medication to stabilise the patient's heart condition; conducting and interpreting diagnostic test results; and understanding the positive and negative effects of different types of surgical and medical intervention.

Patients reported that they were keen to locate the best medical expertise and opinion available to them when it came to clinical diagnosis and any medical and surgical interventions that followed. The importance and value of this type of clinical judgment and expertise was raised by patients particularly in connection with their experience of acute health events, such as angina episodes, heart attacks or symptoms such as breathlessness or chest pain.

'I trusted my cardiologist to do an ablation and cut open my carotid artery under local anaesthetic – he's an expert in the field, so he knows what he's doing.' (Male patient, 81)

'I'm lucky – I live close to a major teaching hospital, so when something goes wrong, I can be seen by some of the top consultants in the field.' (Male patient, 79)

Patients wanted to know that the information they received about medical treatment

was based on the latest research evidence and related to their health priorities, particularly where quality of life might conflict with long-term survival rates.

Once a patient's health had been successfully stabilised through surgical intervention or medication, the need for this kind of expert knowledge appeared to play a much reduced role in a patient's knowledge-seeking behaviour. In terms of Strauss and Corbin's Chronic Illness Trajectory Model (see Chapter 1), the key phases during which patients reported seeking expert knowledge and medical interventions was during phases of disease diagnosis and onset, and in unstable, acute and crisis phases. During stable periods and, to a lesser extent, comeback periods, patients described being much less concerned about seeking the knowledge, advice and interventions of clinical experts. Most of the patients interviewed had experienced stable periods of one year, several years and longer duration: for them, health maintenance had become a greater concern, and expert biomedical expertise played little part in answering their concerns about everyday matters surrounding health behaviours.

'Now that my condition's stable, I'm not going out looking for information. I would if I was worried...on the other hand I bought a bike, but I don't use it anymore and I feel bad about it, but I have an underlying concern that I may overdo it.' (Male patient, 60)

'How much of what I feel is disease and how much is old age?' (Male patient, 73)

3.1.2 Personalised, practical knowledge-seeking: nurse specialists and cardiac trainers

Patients frequently mentioned seeking health-related knowledge from a nurse specialist, cardiac rehabilitation class nurse leader or, to a lesser extent, a cardiac trainer: but what kind of knowledge? Patients who had had exposure to nurse specialists and cardiac trainers as a result of rehabilitation classes tended to be emphatic about how much their knowledge and support had been valued in helping the patient return to normal life following the trauma of a heart or angina attack, and in teaching the patient how to manage their health and daily activities, with nurse or trainer support only when necessary. These health professionals were often spoken of with great emotional warmth by patients and were regarded as less remote than more senior clinicians: they were also reported to take the time necessary to listen and respond to a patient's concerns.

'The nurse has all the information, some consultants don't give a damn....The nurse has time to see the whole person.' (Male patient, 54)

'The consultant says "How are you? What are you taking? Anything major happened? Takes my BP and reads reports and then we're out of time...Nurse practitioners are more hands on, more... empathetic, although many nurses have lost sight of their caring role.' (Male patient, 53)

The kind of knowledge patients associated with nurse specialists and specialist health

trainers can be summarised as *practical personalised health knowledge*: knowledge about how a condition might affect a patient's everyday life, leading to practical information and advice often more tailored to the patient's social and economic circumstances, as compared to the biomedical knowledge and advice dispensed by senior clinicians. This more practical and personalised knowledge-giving was described in different ways:

'Cardiac Nurses...understand heart disease, they're closer to the patient experience'

(Female patient, 68)

'They're more knowing about the real-life things that matter to patients like me.'

(Female patient, 66)

'If I have a query about what I can or can't do, I ask to talk to the cardiac nurse at the YMCA.' (Female patient, 77)

This type of knowledge was of particular use to CHD patients once their medical conditions had stabilised, or to use Corbin and Strauss' trajectory model, in their stable and comeback phases. Patients provided many examples of this type of personalised, practical knowledge from nurses and cardiac trainers: calibrating the type and degree of exercise that might suit an individual patient; lessons in how patients could monitor their own heart rate; advice on how to incorporate low-salt restrictions into an

everyday diet. Such knowledge was underpinned by a strong sense of moral support from the healthcare professional:

'She gave me a sense of confidence and weaned me off having to take my pulse all the time.' (Female patient, age 58)

'I trust the judgement of my community nurse over and above my GP ...people who can help me to know how to live well are more valuable than a GP.' (Female patient, 68)

'When I first had this, I felt very vulnerable: I cancelled my pension, cancelled everything, because I thought I was going to die..... The nurse specialist asked me how I felt...she could see the tension in my shoulders and put her hands on them to encourage me to drop them and helped me to relax...she cared about you' (Female patient, age 63)

Many patients encountered this kind of knowledge-giver in the course of attending a 6-12 week cardiac rehabilitation programme (CRP), which is available to many (but not all) patients once they have left hospital following a major cardiac event such as a heart attack. Participation in such a programme had taken place some years in the past for most of the patients interviewed: many reported feeling unable to successfully manage their longer-term health maintenance, specifically when it came to smoking, diet and regular exercise. Some patients were of the opinion that access to this type of practical, personalised health knowledge had ended too abruptly and that their long-

term health maintenance would benefit from ongoing access of to this kind of knowledge and expertise.

3.1.3 'Folk' or common sense knowledge- seeking: close friends and family, other patients

Many patients placed a high value on knowledge sourced from close friends and family who had little or no medical knowledge or expertise. It seemed paradoxical that many patients regarded friends and family as even the *most* trusted sources of medical knowledge and advice, despite the fact that few patients had any close friends and family with medical expertise, never mind a cardiac specialism. It was easy to understand how family and friends could be a source of moral support and comfort, but less obvious why they should be considered trustworthy sources of knowledge for patients with serious heart disease and often other chronic conditions. Further examination of patient opinions on this topic were sought to explain why many patients with serious cardiac conditions would place their trust in non-expert medical advice and opinion.

Interviews were analysed using the constant comparison method, searching through what points and views were shared across interviews, as well as which views were not. What emerged was that friends and family helped patients with an important aspect of knowledge-seeking: namely, to double-check or supplement medical advice received from health experts against other available sources, or seek out knowledge based on a remedy or palliative approach to a health problem that had worked for someone else.

Friends and family were also important sources of ‘received’ practical wisdom that was used to either supplement or, on very rare occasions, replace orthodox medical treatments. In addition to trusted friends and family, such knowledge was also gleaned from other CHD patients. Health-related knowledge accrued by patients from such sources was not judged by the strength of the scientific evidence base supporting its claims, but by the degree of trust the patient placed in the knowledge giver and his or her assessment of the information in question.

‘My daughter looks up stuff on the internet for me and brings me newspaper cuttings and articles about anything to do with having a heart problem. I trust her to get to the top and bottom of everything. She supports me using HRT even if the doctors don’t want me to.’ (Female patient, 63)

‘I let my wife read all the (health) leaflets and advice – she understands what they’re about and I trust her judgement.’ (Male patient, 70)

Several patients were encouraged by close friends or family to try alternative medical treatments *in addition to* their prescription medication, such as acupuncture, Buddhist meditation, Chinese medicine, herbal remedies, vitamin supplementation, homeopathic tablets and chelation therapy.

'I did nine sessions of acupuncture because my daughter made me do it.' (Male patient, 78)

'There's a homeopath who works in a local bookshop. She asked me how I was and prescribed something to help a bit with my leg. She told me I didn't need to take statins – it can be sorted by the right diet and homeopathic pills - but the GP noticed and made me go back on medication.' (Male patient, 84)

'A solicitor friend gave me a Chinese treatment for diabetes – guava skin and bitter melon. It probably works, but I'm nervous about using it in conjunction with my other heart medication.' (Male patient, 73)

Less controversially, most patients had family or close friends who actively helped them manage lifestyle-related risk factors, notably diet and exercise, by providing advice on diet and exercise programmes based on regimes that had worked for them or for someone known to them.

In summary: whilst a medical expert was highly valued for their biomedical knowledge, experience and clinical opinion, patients valued family and friends as trusted sources of *lay health knowledge*, sourced from both inside and outside the scientific mainstream. Unlike health professionals, friends and family members accumulated knowledge from a wide range of sources: instead of scientific validation, this type of

knowledge was often offered to and valued by the patient on the basis that it was reported to have worked for the person concerned or for someone they knew, or had read about, or seen on television, irrespective of its scientific validity.

3.2 The Internet Paradox: a popular source of medical knowledge is also considered untrustworthy

Patients were further prompted to discuss their most *trusted* sources of medical knowledge and advice, bearing in mind that they could have trust in more than one source. Comparing patient responses to this and the previous response about their knowledge sources generally threw up a paradox that was latent in the previous literature on the topic. The internet was both liked and disliked simultaneously by patients – its accessibility contrasted sharply with the limited availability of medical expertise derived through human interaction – but, at the same time, the information the internet carried was not trusted to be medically accurate.

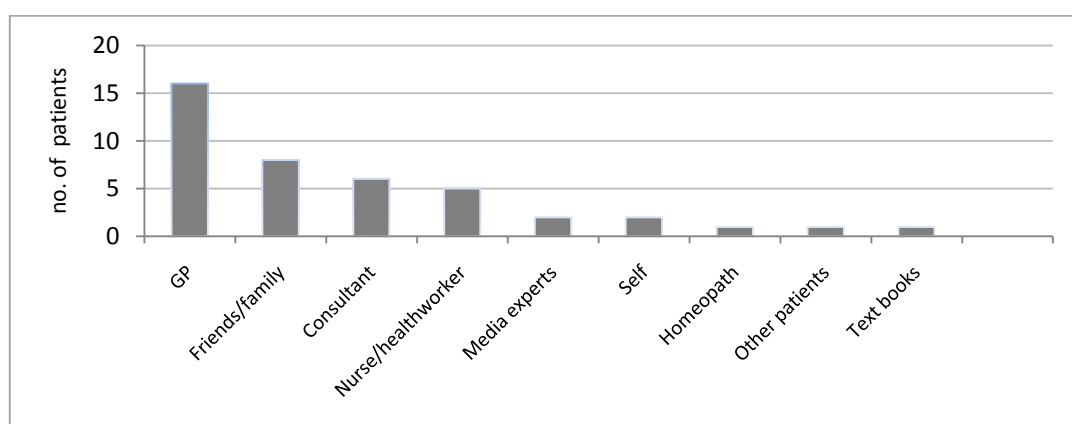


Figure 6.2 Sources most trusted by patients to supply relevant medical information

The internet featured strongly as an important source of patient medical knowledge,

but the internet was not mentioned *at all* when patients were asked to name their most *trusted* information sources. In fact, the internet was generally regarded as one of the least trustworthy information sources, even by those patients who consulted it. These views required closer examination.

3.2.1 Indiscriminate knowledge-seeking

Previous studies contain mixed messages about patient usage and attitudes to the internet. On the one hand, online health information is appreciated for being quick and easy to access, supplying the knowledge not routinely provided by health professionals (Nicholas et al, 2003) and associated with people feeling greater confidence about making health-related decisions and participating during clinical consultations (Eysenbach, 2004; Sillence et al, 2007b).

On the other hand, studies also showed that the public were often overwhelmed by online information for two main reasons: firstly, the sheer quantity of health-related websites available and secondly the problem of information quality or identifying what is medically accurate (Damman et al 2009; Coulter et al, 2006). Interestingly, patients in this study displayed both attitudes simultaneously: despite the fact that most patients reported seeking health-related information from the internet either directly, or indirectly via a friend or family member, not a single patient regarded the internet as a fundamentally reliable information source, due to the problems of information quantity and quality.

The internet was acknowledged by many patients in the study as a useful source of additional information on matters such as the effects and side effects of specific prescription drugs, and medical treatment options, especially as many patients felt such matters had not been explained to their satisfaction by their GPs, or the patient had not been in receptive mental state at the time of the GP visit, due to feeling intellectually intimidated or emotionally upset. The internet was valued by patients for its easy accessibility at any time of the day and the range of information it could provide, as identified by Nicholas et al (2003). However, the easy availability of a wide range of knowledge and information from a range of medical and non-medical sources was simultaneously viewed as a reason not to trust it, as identified by Coulter et al (2006).

I don't look at online information much, even though I use a computer – I'm apprehensive about the sources of the information.' (Female patient, 68)

'My son tells me not to look for information on the internet, as it's not reliable.' (Male patient, 86)

'Online is scary – you can't be sure it's reliable and it can be scaremongering.' (Female patient, 58)

'...it's so vast – mindblowing. On American websites, the treatment is either unavailable or too expensive' (Male patient, 60)

It might be thought that this paradoxical approach might easily be resolved through the use of medically endorsed websites: two of the patients interviewed mentioned searching for medical information using specific health websites, in this case NHS Direct and the British Heart Foundation websites respectively. All other patients who used the internet described how they 'Googled' the internet for health information: in other words, they performed a free search of topics through a popular search engine likely to produce a list of results that would include content from any number of sources, including medically endorsed websites, such as NHS Direct, patient websites and blogs, as well as drugs companies and proponents of therapies unendorsed by a mainstream medical authority.

Interviews revealed that the many patients who used indiscriminate online search methods did so because this was their usual means of seeking online information. However, force of habit alone cannot fully explain patient behaviour: after all, patients could still have chosen to read only health information from reliable sources contained in their search results. When probed further, many patients also mentioned in different ways that they were indulging an intellectual curiosity when reading across such a wide range of internet sources on the subject of CHD and its treatment.

'I was reading around on the internet - I should have had a stress test.....I've read you can partially reverse atherosclerosis with diet.' (Male patient, 58)

'I use the internet to look at diseases and medication. I take it with a grain of salt, but it's very handy.' (Female patient, 84)

'I use Google to search for health information, as it's hard to know what are my symptoms are what are the side effects of the drugs I'm taking.... It's useful when I can find stuff that other patients have posted who have the same problems as me.'
(Male patient, 54)

Patients enjoyed dipping into patient blogs and discussion groups, as well as sites promoting treatments unendorsed by the NHS or rejected by clinicians for being 'unscientific'. However, patients also expressed considerable reservations about web-based information, and stated that they never had and never would try out any new treatment found on the internet without discussing it with someone whose opinion they trusted. Similar attitudes were also reported in studies reporting that the majority of those using health websites stated that they cross-checked the information with doctors, or family and friends (McMullan, 2006; Sillence et al, 2006).

The finding that most of the patients interviewed search the web for health information fairly indiscriminately, using a search engine rather than seeking specific websites, concurs with the majority of studies on the topic. A few patients did indeed

prefer to use sites of recognisable authority, as suggested by Eysenbach et al (2002) and Schwartz et al (2006), but this study cannot state with certainty which attitude is more prevalent among CHD users in general. However, a larger and more recent series of studies report that, increasingly, lay people generally choose to use search engines rather than follow recommendations from healthcare professionals (Sillence et al, 2006; Sillence et al, 2007a) - results that resonate closely with the attitudes of many patients in this study.

3.3 The quality of the GP-patient relationship affects patient knowledge-seeking behaviour

The quality of a patient's relationship with his or her GP was governed by a number of factors described below. Patients provided vivid descriptions of how the quality of this relationship affected their trust in their GP's treatment decisions, which in turn affected patient knowledge-seeking behaviour.

When discussing who or what they trusted *most* to provide the medical expertise and knowledge they required, bearing in mind that they could mention more than one source, nearly half of patients interviewed mentioned their GP as their most trusted source, with 6 mentioning their hospital consultant and 5 others nurses or other related health workers (figure 6.2, previously).

Despite consultants' advanced specialist knowledge and expertise, those patients who described having a positive long-term relationship with their GP often stated a

preference to see their GP. This was for two reasons: firstly, due to the relative ease of access to a GP compared to the waiting time involved in seeing a hospital consultant; secondly, where patients expressed good levels of trust in their GP, they also believed the GP would advise them well and refer them to a consultant when necessary. On the other hand, patients who did not enjoy a good quality relationship with their GP stated an immediate preference for consultant care, or nurse specialist care, depending on the nature of the health enquiry.

Lack of trust also emerged as a significant issue in a patient's knowledge-seeking behaviour. Patient discussions revealed three primary reasons *why* many of them lacked trust in their GPs: lack of GP time; lack of confidence in GP diagnostic skills; and lack of a therapeutic relationship. This is examined in more detail below.

3.3.1 Lack of GP time

There was a common perception that GPs in particular lacked the time necessary to care for their patients, in ways that might sometimes affect treatment decisions and health outcomes. Many patients expressed an acute awareness of the lack of GP consultation time available to them: this sense of time pressure was reinforced by seeing patient queues in the waiting room and having themselves had to queue to wait for a delayed appointment.

'It's not his fault, but when I see the doctor....I feel constrained by the fact that other people are waiting.' (Male patient, 75)

'My business collapsed in 2000...but there's not enough time to talk to the GP about stress – everybody's under pressure. I don't like to complain – I'm not the only one with a problem.' (Male patient, 82)

'I don't trust doctors – I don't underestimate their abilities, it's just due to volume of work.' (Male patient, 55)

'He makes time for me – I apologise for taking up too much time.' (Male patient, 79)

'The doctors are generally too busy to go beyond dealing with the immediate.'
(Male patient, 57)

'The health centre's changed a lot over the years: you never see the same person twice. Some doctors are interested in you, they keep an eye on you – otherwise.....If you look fine and don't complain, they think you're ok and shoo you out...and woe betide you if you have two issues to discuss!' (Female patient, 63)

Patients gave examples of mistakes or problems encountered with GP treatment that they attributed to a lack of GP time: one highly educated professional male in his 50's

reported that he had initially failed to take vital blood-pressure lowering medication after the first month due to a breakdown in communication with his GP:

'The GP gave me a prescription, so I went and got the tablets and I took them...But he didn't tell me that I should have the prescription renewed every month....I only found out when I went back to the surgery a year later and another doctor asked me why I hadn't been taking my medication' (Male patient, 56)

Another patient felt that, in his haste, her GP had referred her to a level of cardiac exercise class that was too strenuous for her condition at the time: attendance at the prescribed class brought on a second heart attack. Eleven patients explained that they had learned to become more assertive over time in order to try and gain the medical attention and treatment they felt they required.

'Don't be afraid to bang the table and ring up doctors....My generation is in awe of doctors.' (Female patient, 67)

'It's important to keep yourself familiar. You need to be able to talk about your treatment so he knows you've checked it out with other people as well.' (Female patient, 68)

'If you don't take an interest, they may take the easiest solution, rather than the best.' (Male patient, 60)

'I played the anxiety card – I've learned to lay it on thick.' (Male patient, 58)

Force of personality was felt to have assisted in, for example, overriding the reluctance of a GP on occasion to refer a patient for specialist medical opinion, or in ensuring that a medical appointment was arranged in a timely fashion by a hospital administrator.

3.3.2 Diagnostic checks

The necessity for diagnostic medical checks and tests was a source of tension between some patients and their GPs, most notably among male patients from higher socio-economic groups, who perhaps had the knowledge and confidence to override GP opinion. Two such male patients described how their GPs had refused to administer tests that the patients wished to have performed, without explaining to their satisfaction why they were being refused. Both persisted and finally received the consultant referrals and tests requested: one patient's concern that he was developing Alzheimer's proved to be unfounded; the second patient had his suspicions that he had prostate cancer confirmed. A further two male patients expressed their lack of confidence in their GP by seeking private medical treatment.

'Going private meant I could expect that there'd be the time and the tests available to really go through what might be wrong.' (Male patient, 60)

One such patient concluded that the private consultation had not in fact led to any overall perceived improvement in their treatment regimen, whilst the other patient felt he was more closely informed as a result of his private consultations.

The concerns expressed by patients here about their GPs should be considered against the view that a judgement about the medical necessity of subjecting patients to diagnostic testing tends to be as much an art as a science. A study that examined requested diagnostic tests concluded that there was substantial variation in the assessment of what constituted an appropriately requested diagnostic test (Bindels et al, 2003). It is clear that these patient concerns were informed by the perception that their GPs were often overwhelmed by their workload. There was concern that overworked medical staff could not be relied upon to accurately convey medical information fully nor perform procedures as well as might otherwise be expected.

'Not all GP's are as good as they should be. They're busy, you need to chase them up.' (Male patient, 84)

'I'm not sure my GP is on top of things...I'm not entirely sure she's au fait with coronary practice.'(Male patient, 58)

'I don't want to be left on the scrapheap, just taking more and more pills – there must be something more they can do – I've got to get a second opinion.' (Female patient, 63)

In these instances, poor trust relations between GPs and patients appeared to lead to increased pressure on GPs for consultant referrals, perhaps motivated more by the patient's power of self-assertion than clinical need. In fact, four of the male patients from a higher socio-economic group in this study openly voiced the opinion that they probably received preferential treatment as a result of their status when communicating with medical staff:

'I'm an educated man...when it comes to doctors, I know how to handle the situation'. (Male patient, 77)

'He (GP) regards me as able to monitor my own affairs.' (Male patient, 81)

'It's unfortunate, but if you're educated and know how to interact sensibly, you're more likely to get the treatment you require.' (Male patient, 60)

3.3.3 Absence of a personal therapeutic relationship

The lack of a long-term therapeutic relationship with an individual doctor also appeared to contribute to a loss of patient trust, in that some patients believed that medical staff who saw them only once or vary rarely would have less reason to care for them and were therefore less likely to make the effort necessary to provide them with the most suitable treatment.

'My GP is one of three, plus some locums ...I have the greatest respect for all of them, but it's not like having a family doctor.' (Male patient, 84)

'The doctor says 'See you in a fortnight's time' – then I see another one.' (Male patient, 81)

'Doctors have no time...They're like machines – I feel pity for them.' (Male patient, 54)

'I don't confide in locums – it's pointless to go through history with them when they don't have time to care.' (Male patient, 88)

'There's a three-week wait to see a specified GP, and none of the doctors in the practice work 5 days a week.' (Male patient, 78)

Previous research confirms that trust in healthcare makes a difference to patient health: trust is known to be important specifically in chronic disease management, where there is likely to be a prolonged relationship between patient and health professionals (Moseley-Williams et al, 2002). Calnan and Rowe (2002) show that trust appears to mediate therapeutic processes and has an indirect influence on health outcomes through its impact on patient satisfaction, adherence to treatment and continuity of care with a provider. These findings also suggest that the patient-GP relationship, patient trust and patient knowledge-seeking are inextricably bound up together.

By contrast, four patients who enjoy a sustained therapeutic relationship with a named GP over time reported feeling fortunate to receive what *they* felt to be privileged access, as they assumed that it was not usual to receive such a high quality of healthcare on the NHS:

'I keep seeing my own GP in Brent, even when I moved to Camden....They warned me that I won't get treatment when the surgery is closed, as I live too far away now, but I'd rather stay with him, as he's known me a long time and understands my health problems. A new doctor wouldn't know me.' (Male patient, 62)

They also seemed to feel less need to seek information from other sources:

'My GP knows enough to say when he doesn't know - and when it's necessary, he's happy to refer me to the cardiologist. I'm happy with that.' (Female, 58)

'My doctor's wonderful at prescribing. You have to be careful of the Red Guards on reception who stop you from seeing the doctor...I don't need to ask anyone else about my health problems – I've got good phone contact with him and he says I can ring him any time. ' (Female patient, 75)

'My GP's more than a GP – he understands things...I see him once a month and he tells me everything I need to know. If he doesn't know, he packs me off to the cardiologist.' (Male patient, 81)

It was interesting to note how such patients assumed that the degree of attention they enjoyed from their GP also meant that they were receiving a better quality of medical care, just as patients who received less time and medical attention were concerned that the quality of their healthcare might be affected. Studies show that it is almost impossible for a patient to assess a doctor's medical proficiency, so they are more likely to evaluate a doctor's behaviour as a proxy measure (Bendapudi et al, 2006). This helps to explain why a time-poor, impersonal GP-patient relationship appears to increase a patient's interest in seeking knowledge elsewhere: GP behaviours perceived by the patient to indicate a lack of time or personal attachment are associated with reduced quality of care. This, in turn, may increase their need to question and double-check their GP's treatment decisions elsewhere.

3.4 Poor patient communication with healthcare professionals affects knowledge-seeking behaviour

Poor communication with healthcare professionals encountered in the course of treatment contributed to the erosion of patient confidence and trust in their healthcare, causing them to seek knowledge elsewhere or to check medical information provided with family and friends or on the internet.

It would be wrong to fail to mention the gratitude expressed by many patients regarding the medical interventions and medical staff that they felt had saved their lives, particularly after an acute event such as a heart attack. However, alongside the admiration for the work carried out by many healthcare professionals, patients also

expressed disappointment at the poor levels of communication encountered, with just under half the patients interviewed expressing the desire for clearer communication of medical information.

'I haven't seen the hospital consultant since the diagnosis...I've no idea who's meant to co-ordinate the care: I think there's a care manager, but I've never met them.' (Wife of male patient, 75)

'The doctor showed me a bone fracture on his computer screen – I thought it was my bone he was showing me, but it turned out it was just a picture!' (Male patient, 77)

'I didn't know I was a heart patient till you said I was on the (CHD) register.' (Male patient, 88)

'My GP sometimes assumes the consultant's informed me about something and vice versa.' (Male patient, 53)

'The doctor has never explained why I have hypertension, although I assume it's got something to do with my weight, as they delayed treatment to see I could reduce my weight to bring my BP down.' (M, 57)

Over a third of the patient group declared themselves to have been unhappy with some significant aspect of the medical advice received from a GP or hospital specialist:

these patients felt that they had not received the right medical information in a timely way when they needed it; or that the information they had received had been too general and not relevant to their specific needs or medical condition; or that the information as they had understood it turned out to be wrong or inaccurate. Four patients stated that they had changed their GP as a result of disagreeing with their medical opinion or attitude.

Just under a third of patients expressed concern about the attitudes of health workers they had been exposed to. There was a general understanding expressed by the cohort that consultant time is generally only available to investigate and treat new and existing medical symptoms, rather than provide a forum for discussing patient concerns that fall outside these parameters, such as a lifestyle related issues, or other concerns that relate to managing their condition. However, consultant behaviour perceived as offhand or arrogant was mentioned by 4 patients, who felt that such behaviour had actively discouraged them from seeking clinical information about an aspect of their care they had not understood.

'I read an information pack in hospital and I was worried about medicine incompatibility, but the hospital doctor wasn't happy when I questioned him about it. He looked at me as if to say "Who are you?" – but surely any doubt should be raised?' (Male patient, 86)

The attitude and communication skills of district nurses were questioned by most of those interviewed who had been exposed to them over a protracted period of time. Language barriers and rough handling were cited by three out of four patients who had frequent exposure to district nurses and all expressed concern about raising the matter, even in an anonymised interview, for fear of being thought racist:

'One district nurse thrombosed my arm when she was taking blood and I found her a bit rough and bullying. When I complained, I was told 'you don't want my colleague because she's black' and I was warned that the service would be taken away from me if I was prejudiced. Me! I was married to a West Indian and I've brought up mixed race children...I was fighting prejudice before they were born, but I didn't feel able to report problems anymore.' (Female patient, 75)

By contrast, nurse specialists were singled out for praise by five patients who had had regular access to them. Nurse specialists were viewed as combining significant medical knowledge with time available to discuss it, as well as practical expertise that hospital doctors might be unaware of or too busy to discuss, and as such, demonstrably closer to the patient experience in ways that were highly valued by these patients. Most patients who had encountered nurse specialists and cardiac trainers expressed a liking for their manner and attitudes.

'After the operation, I felt as if I'd been mutilated, butchered...there were scars on my chest and legs....but the nurse made me feel completely looked after..it gave me the confidence I needed to carry on.' (Female patient, 63)

'The trouble is, it's terrifying having a heart attack. You lose faith in your body. You don't know how to interpret what you feel any more. You need someone who can understand that phase.' (Male, 58)

Despite their lack of medical expertise compared to a consultant medical specialist, nurse specialists were widely held to be knowledgeable in their areas of expertise and strong on social support.

3.5 Secondary knowledge-seeking

Patients also identified a second tier of knowledge-seeking: the kind of knowledge sources that provided generalised knowledge and information, not tailored to the specificities of a patient's individual medical condition. As such, patients tended to describe such knowledge sources as providing the kind of raw information they gathered in order to discuss further with clinicians or friends and family.

3.5.1 Health literature: background information

Patients said they consulted CHD information leaflets and newsletters from the NHS or the British Heart Foundation when found in GP surgeries or elsewhere; but most

regarded such literature as either too generic or too simplified to be personally useful to them.

Written information in the form of leaflets and health literature generally provoked less enthusiasm than knowledge derived through personal interaction or the internet. Patients were sceptical about the relevance of much of the generic written information they had encountered, as it was by nature unable to address the specificities or complexities of their disease as it was experienced by them.

'Information is available, but I'm not a normal patient – it needs to be geared to the level of what the person is seeking.' (Male patient, 53)

(of NHS leaflets) *'The info's pretty useful - but very minimal.'* (Male patient, 60)

'I like brochures, as long as they're not too simplistic.' (Male patient, 57)

'They issued me with a wallet of information, but lots of the details aren't up to date.' (Female carer, 65)

This finding is echoed in previous studies, where patients have been critical of the value of generic written health information that was not personalised to them (Murie et al, 2006; Yamanda et al, 1998). Patients were also concerned that such printed material might also be out of date, in terms of latest procedures or clinical guidelines.

Books about CHD were read by two of the patients interviewed: rather than being an authoritative knowledge source, books were viewed as authored and therefore partisan raw material to be discussed with a doctor or other medical specialist.

'The trouble with reading is that it's hard to get a professional feel. You need to talk too.' (Male patient, 58)

However, pressure of time in GP surgeries was often mentioned as a reason that such discussions were either unsatisfactory or never actually took place.

3.5.2 The mass media: stimuli to immediate action

Knowledge gleaned from the mass media was regarded with considerable ambivalence. Television and newspaper information elicited a paradoxical response reminiscent of the conflicted attitudes patients had expressed towards the internet. On the one hand, patients were quick to express their disapproval at how the media liked to promote scare stories:

'I treat the health industry with contempt...they conduct studies, want to make their mark and issue alarmist statements. Then the press joins in.' (Male patient, 79)

On the other hand, the popular media was considered influential by patients in two respects: firstly, because it was demonstrably able to disseminate new medical

information to patients very quickly, albeit in a sometimes emotive rather than objective fashion; secondly, because it was seen by some patients as a means of accessing the opinion of 'top medical experts'.

'I read something on the front of the Daily Express, which said that experts think aspirin is dangerous, because it affects the brain – something about micro-cells leaking into the blood. Specialists are mentioned in the article and I prefer to take precautions on the basis of what I read.... I mentioned this to my doctor, who asked for a copy of the article, but he didn't say anything more about it. Y'know, someone like me doesn't get to speak to top medical experts, but I can read what they say in the papers.' (Male patient, 77)

In four instances, medical information in the news and in the press had been preferred by patients to their GPs' medical opinion and acted upon without recourse to checking with a doctor first. One patient ceased to take the daily dose of aspirin prescribed by his GP when he read a tabloid news report in June 2009, warning that a major study had shown that the risks of taking aspirin outweighed the benefits for some patients. He discontinued taking aspirin despite his GP's entreaties.

A 58- year old patient with a history of heart attack and stent surgery expressed a critical attitude to the media in general, but went on to describe how she had discovered the dangers of her taking her prescribed analgesic:

'I was prescribed Vioxx for my painful joints...But then I saw news reports on the BBC that talked about a clinical trial that showed how Vioxx increased the risk of heart attack, and I stopped taking it. ... It was only some months later that I got a letter from my GP telling me to stop taking it.' (Female patient, 58)

News stories also provoked a further two patients to demand diagnostic tests on the basis of news reportage about Alzheimer's and prostate cancer, as discussed earlier.

On the basis of first-person stories, coupled with facts and expert opinion, the popular media was successful at encouraging some patients to take *immediate* actions on health matters that might carry significant health risks, such as ceasing to take a prescription drug, or insisting upon access to a specific diagnostic test. None of the stories told by patients suggested that the media had been influential in stimulating repeated actions over a *sustained* period, such as for example those actions required to change long-term behaviours that also carry significant health risks: rather, media alerts were able to provoke major one-off decisions.

3.6 Patient use of 'alternative' medical remedies and therapies

Use of alternative medicine was quite frequent among the patients interviewed, but largely confined to supplementing, rather than replacing mainstream pharmaceutical products and advice. Many patients did not regard the absence of scientific evidence of their efficacy as a reason not to try alternative medical therapies, as long as such

therapies and associated medication did not interfere with their prescribed medication. Personal recommendations from friends and family and self-experimentation tended to guide their decisions about which therapies to try.

'I take green-lipped mussel extract for aches and pains – it was recommended to me by a university friend.' (Female patient, 68)

'I take glucosamine for stiff joints – my brother-in-law swears by it.' (Female patient, 63)

'Someone I used to work with said I should take a multivitamin because of my age.' (Male patient, 82)

'D- from the Irish Centre tells me that when wheat is growing, they put 17 chemicals on it, so I try to eat organic food. She recommended Manuka honey – it's certainly improved my hair and nails.' (Female patient, 84)

A third of patients interviewed reported that they took some form of alternative medicine *in addition to* medication prescribed by their GP or hospital consultant to alleviate symptoms of poor health. Almost two-thirds had never taken any kind of alternative medicine or therapy to alleviate symptoms of poor health; two patients had resorted to alternative medicine in the past, but no longer did so. Three other patients had considered taking an alternative medicine or therapy, but had decided not to proceed in case of interactions with existing medication.

Only one patient had attempted to *substitute* alternative medicine for prescribed medication; in this case, one patient had ceased to take a daily statin and instead substituted a remedy recommended by a homeopath to lower cholesterol, quote earlier in this chapter. The patient had done so because he associated his statin intake with a loss of muscle above the amputated section of one leg, which caused further health problems, including a bad fall, as the leg prosthesis no longer fitted properly. His GP eventually persuaded him to switch back to his statin: a medical decision about how to deal with the ensuing problems with his leg had yet to be made.

When questioned about the lack of an evidence base for the efficacy of many alternative therapies, patients were candid about their willingness to experiment with treatments, even if they did no good or only had a placebo effect, as long as they felt such treatments were unlikely to cause them active harm. Some also voiced their appreciation of the caring behaviour of alternative therapists, often absent from their experience of NHS medical practice.

'The Homeopathic Hospital has a different feel – it's calm and peaceful...The doctor asks about the whole person....Scientific medicine is so highly specialised that no-one looks at the whole person.' (Female patient, 66)

Views such as this are echoed by Angell et al (1998), who state that the attraction of alternative medicine is partly a result of 'disillusionment with the often hurried and

impersonal care delivered by conventional physicians, as well as the harsh treatments that may be necessary for life-threatening diseases.’

In the light of public debate about the poor value and lack of efficacy of homeopathy and alternative medicine generally, it is worth stressing that, with the exception of one patient, those seeking alternative medicine or therapy viewed it as supplementing their orthodox medical regime rather than replacing any element of it. In fact, alternative therapies were overwhelmingly sought out by patients in order to deal with symptoms that orthodox treatments had *failed* to manage successfully, such as chronic pain, joint stiffness, muscular cramps, fatigue and depression.

Interest in alternative medicine co-existed alongside a respect for orthodox medicine: many patients expressed frustration that their doctors were closed to the idea of alternative medicine, especially where it was used to manage symptoms that orthodox medicine had proved unable to resolve.

‘I’ve read the theory behind it and scientific studies – that water has memory, water records information. I can see both sides of the argument...Both sides are rather insular.’ (Male patient, 84)

‘Most doctors sneer, but it (homeopathy) works.’ (Male patient, 79)

'People swear by it. We have to be open-minded – it might work for you.' (Female patient, 58)

'I have my own views but I'm always open to suggestions and information. I don't know loads of things, I'm not brilliantly intelligent. I'm open to trying things, but also rejecting them.' (Female patient, 63)

In reality, the idea that there are two types of medicine – conventional and alternative – is a false distinction, as there is only medicine that has been tested for its efficacy and effectiveness and medicine that either has not been tested or has been tested and rejected on the grounds that it is not efficacious (Angell et al, 1998). On the basis of patient attitudes expressed in this study, the power of the idea of 'alternative' medicine is perhaps best explained as a combination of two patient motives: it expresses the confidence of the patient, willing to experiment with unproven treatments to alleviate unpleasant symptoms of illness, irrespective of medical expert approval. It also expresses a cultural outlook that is unconvinced by or unaware of the often overwhelming evidence against the efficacy of many 'alternative' treatments.

3.7 NHS-held patient data

Patients showed little interest in accessing the NHS data held about them, either in

patient health records or at their GP surgeries. This appears to contradict the widely held political expectation that patients might want greater access to such data.

Patient knowledge-seeking tended to exclude any interest in access to the content of their health records. No patient spontaneously mentioned a desire to see their health records in the course of discussing their knowledge-seeking activities; when prompted, there was little enthusiasm. 5 out of 35 patients did express some interest in having access to their health records: all 5 were patients who had described particularly negative experiences of their medical care in the past – all wished to access their health records to check them for accuracy, rather than to be provided with additional health information. Patients reported that they already receive copies of all correspondence between their hospital consultant and their GP following a consultation and that this sufficed, particularly as the information in the consultant letter was often hard to understand.

'I feel soused by information and letters from the hospital.' (Male patient, 84)

'I have a whole sheaf of consultant letters...can't say I understand them much.'

(Male patient, 73)

Shared screen technology was raised with patients, as it was widely reported to be a useful tool, much appreciated by patients when trialled in Haughton Thornley Medical Centre in Manchester. Only 6 out of 34 patients expressed an interest in being able to

look at their GP's screen during a consultation, with 2 patients declaring that they already did so by leaning across and looking when they wanted to.

'I take an intelligent interest in my health, but I don't want to get too involved.'

(Male patient, 73)

Some patients voiced the view that there was something potentially unhealthy about immersing oneself in too much health data:

'To even think about reading your own health records...well, it smacks of paranoia...if someone has trained as a doctor, they can form a diagnosis without my input.' (Male, 68)

'I'm worried it might turn me into a hypochondriac – but if it was NHS-directed, then I suppose it might be OK.' (Female patient, 58)

Many interviewees expressed conflicted views about accessing their medical files and other data held on them by their GP and hospital doctors. Whilst demonstrating a high level of understanding and awareness of their medical conditions, many patients voiced the opinion that knowing too much might be 'unhealthy' and that there was an area of medical knowledge germane to a health professional that they did not feel it was right or necessary for them to know about.

(Of self-management) *'That kind of thing might make me obsessive and encourage hypochondria.'* (Male patient, 56)

3.8 One size does not fit all: patient responses to Cardiac Rehabilitation Programmes

The only knowledge-management related intervention that had been offered to some of the patients interviewed was the cardiac rehabilitation programme (CRP): 13 out of the 14 patients who had been offered it, had attended a CRP following release from hospital after a heart attack or stroke. Such programmes had consisted of 6 to 12 weeks of weekly health education classes regarding post-operative diet, physical activity, relaxation and self-care, as well as around 6 weeks of weekly exercise in a hospital or local authority gym, supervised by a fitness instructor with an expertise in exercise for cardiac patients, with the aim of equipping the patient physically and mentally for living as fully as possible with a chronic heart condition.

There was broad support for the aims of such classes among the patients who had attended a CRP: almost all felt they were worthwhile and imparted useful information. However, the 'one size fits all' approach led some patients to cease attending: what was welcomed by some patients was actively disliked by others. So for example, all 3 women who had attended a CRP and 5 of the men actively enjoyed the group aspect of it. 2 female patients in particular described how they had benefitted from an ongoing relationship with the patient group they had met through cardiac rehabilitation. The

ongoing camaraderie, and being able to meet and socialise with people with similar health conditions was described as providing moral support and mutual care. For some, it also seemed to engender optimism to see other patients making positive efforts to re-gain control over their lives.

'You meet other people and you're not on your own...other people suffer in different ways. Communicating stops you feeling sorry for yourself and gives you moral support.' (Male patient, 81)

'I got into a good group of heart patients. We've stayed together and we give each other moral support as well as meeting to exercise over the last five years....When I'm feeling a bit arthritic, I look at some of the others. And that gives me heart.'
(Female patient, 77)

'We all looked out for each other a bit...we were able to say to one man that he was looking a bit grey around the mouth and should take it easy....ordinary people might not even notice; a doctor might not feel able to say such a thing out in public.'
(Female patient, 68)

For some, most notably some of the older and more educated men, the group aspect of rehabilitation therapy was a disincentive. These patients reported that they had valued the cardiac rehab classes they had attended for restoring their physical confidence and teaching them some useful practical information; however, they did

not enjoy the social aspect of being grouped with other patients and, unlike some other patients did not seek the company of other CHD patients on a longer-term basis.

'Twenty ageing, gasping people, all made to do exercises...it was like being back at school.' (Male patient, 77)

'It's not suited to me: most of them were worse-off than me.' (Male patient, 86)

'I found it a bit strange to be in a classroom situation with other people...I wouldn't want to meet any of them again.' (Male patient, 70)

In addition to the issue of the format's lack of appeal, 3 patients reported that the CRP they had attended had failed to address their specific needs. One male and one female patient suffered serious heart problems at 47 and 46 respectively and were still in full-time employment. When they attended CRP, both described their shock at walking into a room of elderly retired people.

'Everyone else there was much older...the elderly have nothing to do, so they talk....they said to me 'you're too young to be here...I went once.' (Male patient, 54)

'It was a very diverse group - some people's aim was just to get through the day. I felt mean discussing some things that must have seemed irrelevant to retired people, like managing a busy working week.' (Female patient, 58)

The female patient concerned had to discontinue rehabilitation classes because she was unable to make the class times fit around her job over the 12 week period following release from hospital. One other patient had felt unable to attend any of the CRP he was assigned to, due to the need to return to work.

In spite of criticisms, the advice and support available to patients during the period of their rehabilitation classes was welcomed: many felt that there was a need for some kind of ongoing health maintenance support with diet and exercise once the CRP had ceased.

3.9 Knowledge-seeking and patient self-care

Since 2003, the Department of Health has encouraged GPs to increase levels of patient self-care among those with a chronic condition. Despite this, there was very little evidence of active encouragement by GPs of even elementary self-management measures such as home blood pressure monitoring among the patients interviewed - even among the younger, less sick and more educated patients, who might arguably be deemed more able to manage such a task.

3.9.1 Blood pressure monitoring

On the subject of blood pressure monitoring, most patients declared themselves content to leave its measurement in the hands of their GP or practice nurse. 5 patients out of 34 were taking their own blood pressure (BP) readings using home monitors on a regular basis; 2 out of the 5 were monitoring their BP on the advice of their GP. Only

3 actually reported their findings back to their GP surgery. 2 other patients had previously monitored their BP but had given up doing so.

Patients reported that, with 2 exceptions, their GPs had not actively encouraged them to monitor their own blood pressure, but that readings were taken in the GP surgery on a monthly, bi-annual or annual basis. Only one patient who monitored his BP had been trained to do so by the practice nurse; two had only been advised how often they should take a reading. Four out of 5 patients who took BP readings had learned to do so by following the instructions that came with the monitor when purchased.

The investigator observed three patients take blood pressure measurements in their homes: one used a wrist cuff, which is not recommended for an accurate reading. He was unsure exactly what to do and asked the investigator for advice on how to use the monitor properly. The other two patients observed were quite proficient at taking a digital reading and were able to explain what they were doing and why when arranging the cuff on the upper arm and placing the lower arm on a table.

Diabetes patients demonstrate that patient self-monitoring is possible, as all are taught to monitor and manage their blood glucose levels. Studies show that patient BP self-monitoring correlates with improved BP management when compared to GP practice monitoring (Agarwal et al, 2011; McManus et al, 2010): however, despite the widespread availability of BP monitors in high street chemists, such evidence appeared

to have made little impact on the extent of GP encouragement to self-monitor among the patients interviewed. This was also reflected in the GP questionnaire responses.

There was little enthusiasm among the patients who did not monitor their BP to do so, some expressed a sense of it somehow overstepping the mark between patient and health professional.

(of measuring own BP): *'It's like stepping on the toes of your doctor – y'know, the people who are there to do it and know what they're doing.'* (Female patient, 56)

It's hypochondriacal to measure one's own BP – I leave my blood pressure to the professionals.' (Male patient, 79)

'I fear it might make me a hypochondriac.' (Female patient, 58)

'I did wonder about buying a BP monitor, but I've no idea what to buy...I'd feel foolish asking the GP – it would be over the top.' (Male patient, 56)

This may be an good example of what is termed the 'asymmetry in rights of access to knowledge' (Heritage, 2006). Referring to a layperson's sense of a lack of entitlement to medical knowledge, Heritage states that 'In institutional interaction then, knowledge may not be enough; one must also be entitled to the knowledge, and have come to it in an appropriate way.'

3.9.2 Cholesterol levels

All patients had their cholesterol levels measured at their GP practice: most reported only a vague recollection of their last reading. All but 6 patients could remember whether their most recent cholesterol test had been pronounced within normal limits or not by a GP or practice nurse, and 6 patients thought they could recall the exact figure from their last cholesterol reading. The information was not checked for accuracy with their GP, as it was considered here, along with other elements of health monitoring, as an indicator of each patient's degree of engagement with their ongoing healthcare.

3.9.3 Body weight

32 out of 34 patients weighed themselves on scales at homes and were able to confidently provide details of their body weight: again, no attempt was made by the investigator to verify the actual figures. Over half of the cohort considered themselves overweight, which corresponded with the visual assessment made by the investigator. Of the 18 patients who considered themselves overweight and who appeared to be noticeably carrying excess body fat, all stated without prompting that they were actively trying to reduce weight, in line with written or verbal medical advice some had received from their GP or consultant.

Apart from a few instances of blood pressure monitoring and attempting to follow verbal or written medical advice, none of the patients interviewed had been involved in any interventions designed to encourage patients to take a more active role in co-

managing their CHD. No-one had received exercise prescriptions, referral to self-help groups, any kind of telecare such as online or phone reporting of blood pressure measurements, or any kind of interactive health communication application (IHCA). Patients reported feeling unsure whether an increased involvement in their healthcare was actually appropriate, as many considered key aspects of their own healthcare to be medical territory that belonged to their GP.

The lack of knowledge management interventions offered, coupled with a distinct sense of patient lack of entitlement to self-manage their condition, suggested that there may be a significant gap between the research literature reviewed in chapter 3 and GP practice. In response to this finding, it was decided to ask GPs in Camden PCT to report more broadly on which interventions they used with CHD patients: the results are discussed in chapter 8.

4. SUMMARY OF MAIN RESULTS

An analysis of patient interview data relating to the research question: 'What sources do CHD patients use when seeking knowledge about their condition, and what are their reasons for doing so?' produced the following 8 results:

4.1 Patients sought three different types of knowledge from different knowledge sources: firstly, expert knowledge from GPs and consultants; secondly, personalised practical knowledge from nurse specialists and, to a lesser extent, cardiac trainers;

thirdly, 'folk' or common sense knowledge from close friends and family and other patients.

4.2 The Internet Paradox: a popular source of patient medical knowledge was simultaneously regarded as untrustworthy.

4.3 The quality of the GP-patient relationship affected patient knowledge-seeking behaviour: patients who lacked a long-term positive therapeutic relationship with their GP were more likely to seek knowledge elsewhere. Poor communication with healthcare professionals also influenced patient knowledge-seeking behaviour. By contrast, nurse specialists and cardiac trainers were singled out by many patients as good communicators.

4.4 Secondary knowledge-seeking: patients tended to regard written general information about CHD as less relevant to them, as it could not address the specificities of their condition. However, press alerts that contained healthcare warnings requiring a fast response had been demonstrably influential sources of patient knowledge.

4.5 Patients reported using a range of alternative medical remedies and seeking medical advice from alternative therapists. Alternative medicine was generally used to supplement, rather than replace orthodox medicine: its use by patients in this way appeared to be unaffected by any evidence presented regarding its lack of efficacy.

4.6 Despite considerable engagement with their healthcare, the prospect of having access to NHS-held patient data, such as health records, was of limited interest to patients, as they already felt overwhelmed by information that was of limited use to them. There was also a feeling among patients that there was something inappropriate about patients being too involved in medical aspects of their treatment and that it intruded onto terrain occupied by health professionals.

4.7 One size does not fit all: patient responses to Cardiac Rehabilitation Programmes showed that, whilst some patients, notably but not exclusively women, actively enjoyed and appreciated the CRPs they had attended, some of the younger CHD patients still in employment and some of the older, more educated men had felt out of place. In addition, the health maintenance support provided was felt by many patients to end too soon.

4.8 Despite evidence of patient engagement and very high levels of prescription drug adherence, there was little indication that patients felt encouraged by their GPs to play a more active role in managing aspects of their CHD.

The implication of these findings for knowledge-seeking among CHD patients and knowledge management interventions aimed at CHD patients will be discussed in chapter 9.

CHAPTER 7 | RESULTS (2):

DO CHD PATIENTS, IN THE COURSE OF MANAGING THEIR CHD, GENERATE KNOWLEDGE ABOUT THE CONDITION AND ITS TREATMENT?

1. INTRODUCTION

The focus of investigation now shifts to the second research question: do patients, in the course of managing their CHD, generate knowledge about the condition and its treatment? In section two of this chapter, the author develops a theoretical model, based on the application of knowledge management theory, to help explain the mediations between patient knowledge and organisational knowledge. Section three reports two findings based on patient-generated knowledge: the first examines the significance of patient-generated health records; the second result analyses how patients make sense of the relationship between their health knowledge and their health-related behaviours. The chapter concludes by summarising these findings.

2. PATIENT-GENERATED KNOWLEDGE AND ORGANISATIONAL KNOWLEDGE CREATION

2.1 The nature of patient-generated knowledge

Patient knowledge production is, by its very nature, partial and subjective; but patients can provide the kind of information that cannot be drawn from any other source. The

patients interviewed for this study, in common with many of those living with long-term conditions, are a very special type of community of interest: they are the only people in the healthcare process who are likely to experience a care pathway from start to finish, across primary and secondary care, over a protracted period of time; they have a vested interest in improving the services they use; they may desire treatment outcomes that differ from outcomes measured and valued by a clinician; they develop a knowledge about their disease and its management that is based on their own powers of self-observation and experience of the healthcare process; they are not remunerated, nor do they receive any kind of social advancement for their developing expertise in managing their own healthcare; and their approach to healthcare is motivated by a range of different and highly subjective factors. It is for these reasons that the author anticipated that CHD patients might generate knowledge about their condition that springs from the unique position they hold as both health service users and co-managers of their own health.

2.2 The application of KM theory to patient knowledge

This section sets out the author's application of knowledge management theory to the field of patient knowledge and its role in organisational knowledge creation. The study revealed that patient knowledge can be explicit or tacit: it is obviously explicit when the patient is aware of the knowledge he or she possesses and is able to articulate that knowledge, in the form of an observation or an opinion. Explicit patient knowledge can also have immediate organisational relevance, especially if that subjective knowledge is replicated by many other patients. So, for example, a number of CHD

patients observed that they had encountered specific problems regarding continuity of care across specialities. When such observations are repeated by a number of patients, this indicates that there may indeed be objective problems with continuity of care across specialties from a patient point of view which merit further enquiry.

Patient-generated knowledge can also be tacit; tacit knowledge is necessarily personalised, bound up in what a patient has done or experienced in the course of managing their condition. Embodied, tacit patient knowledge can exist at the level of patient practice and such knowledge may be regarded by the patient simply as 'what I do and how I do it' rather than 'what I know'. Patient activity can give tacit knowledge expression: an engaged observer can draw out, distil and convert the knowledge that underpins the observed activity by further interrogating it with the patient. For such patient knowledge to have organisational relevance, it may need to be observed in numerous patients and the patterns of patient knowledge distilled and refined by the observer. These acts, by the patients and then by the engaged observer are the steps that make tacit patient knowledge accessible and therefore of possible significance to an organisation.

The patient knowledge map set out below in figure 7.1 shows the different forms that patient knowledge can take and the direction of travel as tacit knowledge moves between the different axes.

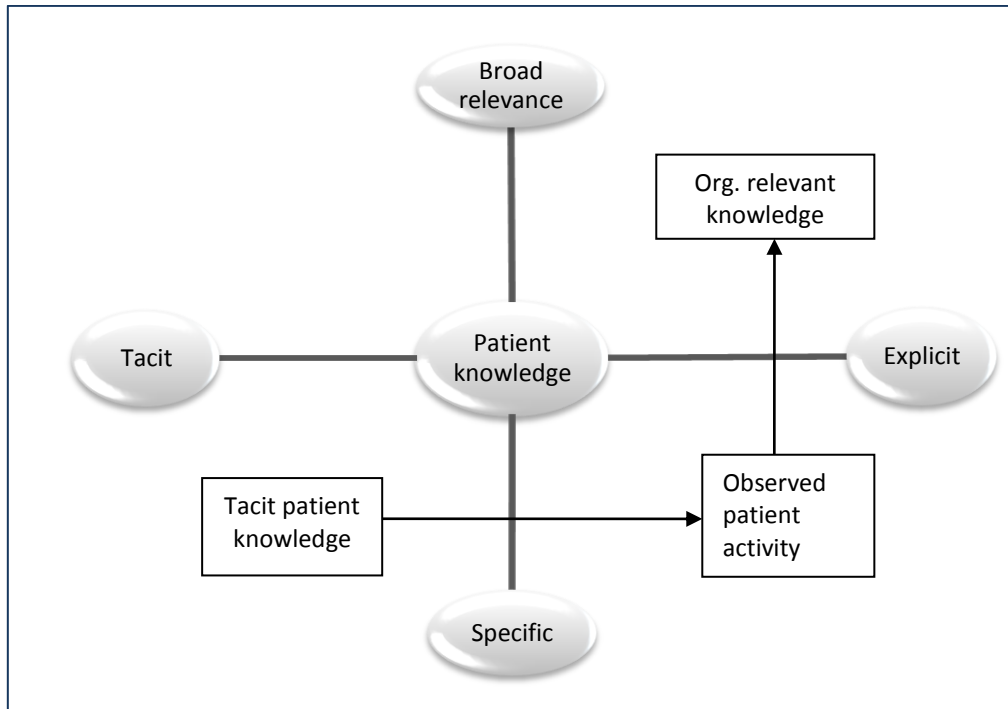


Figure 7.1 The Patient Knowledge Map: tacit knowledge conversion

Tacit knowledge generated by patients in this study and described and analysed later in this chapter, was converted into explicit knowledge of potential organisational relevance through the agency of the study's investigator/author, the engaged observer. Such tacit knowledge took an observable form, in the shape of patient activity in the author's presence, and was replicated by a number of patients: this enabled the author to question them about this activity and trace the activity back to the patient-generated tacit knowledge that underpinned it.

The patient knowledge map will be used to depict the knowledge trajectory involved in the patient-generated results reported in this chapter.

3. RESULTS

3.1 Patient-generated knowledge: home-made patient health records

The author observed a good example of patient knowledge creation in relation to patient record-keeping. This example also served to demonstrate the relationship between tacit patient knowledge and organisational knowledge creation.

3.1.1 The Patient Experience

Patients provided many good examples of individualised explicit patient knowledge, generated in response to their experience of trying to negotiate the administration of non-acute CHD healthcare in hospitals.

Systemic failures and inefficient health administration are particularly likely to affect the treatment of chronic disease patients: as long-term and repeat users of healthcare facilities, they are well-versed in what can go wrong. The perceived excellence of acute medical treatment seemed to make it harder for many patients to voice their dissatisfactions about other aspects of healthcare:

'...it seems a bit ungrateful to moan on about this kind of thing...if it wasn't for the NHS, I probably wouldn't be here now.' (Male patient, 78)

However, in contrast to the glowing accounts of the emergency treatment received when they had suffered an acute incident such as a heart or angina attack, many

patients described their disappointment at the administration of non-emergency treatment. The bulk of patients interviewed detailed the frustrations of long-term chronic healthcare: repeatedly cancelled outpatient appointments; online appointment systems that don't work; diagnostic tests scheduled in such a way that they are unavailable for the date of the consultant appointment where they were to be discussed; doctors' apparent lack of time available to discuss patient concerns; the failure to hand over patient cases efficiently from one clinician to another when consultants move on from a their hospital post; and the lack of coordination between clinical specialties when treating patients with multiple conditions. Patients described in different ways a sense that their care was proving too complex for the systems set up to manage it.

'The endless postponed hospital appointments are very muddling and sometimes I get out of my depth. The last time we saw the consultant he found a skin lesion and said we should ask for the next appointment to be brought forward – but when we asked the appointments people they told us it wasn't possible.' (Wife of male patient, 78)

'Sometimes there are no nurses available to re-dress my legs when the doctor has examined them.' (Male patient, 78)

'Nowadays, I inform my GP when I'm going into hospital, I ensure letters are sent to the right people and I write the GP a note to let him know I've been discharged.' (Male patient, 53)

'In the system, particularly with hospitals, you do have to look after yourself. You have to check out where you need to go, where to order tests, how to track them down if they forget to give you the result. I know what to do now – I recently had to write a three-line letter when I fell off the cardiac lists.' (Male patient, 77)

In many cases, the patient or spouse has to actively intervene in complex hospital administration systems in order to try and secure diagnostic assessments and non-acute treatment in a timely fashion. Patients with multiple conditions often struggle to manage the administrative and organisational burden of their healthcare.

Many of the patients interviewed had vivid examples of the ways in which they had had to intervene in the administration of their healthcare in order to chase hospital referral letters or test results lost in transit; to ensure consultant letters were made available to relevant clinical specialties; to co-ordinate the timing of test results to coincide with consultant appointments; to check medication regimes prescribed by one specialist against the treatment advised by a specialist in another clinical specialty; to try and re-organise appointments that had been cancelled or forgotten.

'There was an admin cock-up at the hospital and I had to press to carry my business in the cardiac department forward – I could have fallen through the net – I'm not sure what would have happened if I'd been a dotty old lady on my own. ' (Male patient, 77)

'I had a heart scan in February and I wasn't seen to discuss the results until May. I was told in February I needed an angiogram in the next 2 weeks, then I heard nothing.... so I emailed the cardiology department and eventually an email came back which had done the rounds of various people – the angiogram is now on 11th June. (Male patient, 55)

'If you want to make sure you don't fall between the stools, you have to keep ringing people up.' (Male patient, 58)

'There are parts of the NHS that are not wonderful, like the connections between one department and another....When I was discharged from hospital, the handover process was chaotic. I'm meant to have had a blue folder for district nurse home care since treatment started in January...well, that's what? Six months ago?' (Male patient, 84)

These kinds of problems cause a considerable burden of work and stress for many of the patients interviewed, and were particularly in evidence among patients with the most complex health problems, who are also likely to be the sickest patients and therefore the least able to struggle with such organisational problems.

3.1.2 The discovery of home-made patient records

In the course of interviewing patients in their homes, the author noticed that, over

time, many of the patients interviewed had come up with a common, if individualised, response to the raft of organisational healthcare problems facing them.

The author had given patients the option of where to be interviewed: 30 patients opted for a home visit. Home interviews enabled patients to 'show and tell': the author was shown what one patient was having for dinner, the bed where a partner had died, the sheet of 'impossible' exercises handed out by a hospital physiotherapist, the box of food set aside for the birds outside the window of one housebound patient, home medical equipment, and the array of receptacles patients used to store their prescription drugs.



Figure 7.2 Patient's tin of medication and daily doser

In the course of visiting patients in their homes, it came to the author's attention that during the interview, many of the patients retrieved some kind of notebook, diary or file. At its most basic, the notebook consisted of a detailed list of medication and dosages. The notebook was often carried around in a pocket or handbag: patients

explained that they often came across health professionals who had no access to their health records but needed to know what medication they were taking – for example, when the patient attended a dental consultation, or bought over-the-counter medication, or where health records were lost or unavailable during a hospital consultation.

23 out of 34 patients had devised more elaborate home-made records: on the basis of past experience, many patients had collated the information they might need in the event of a breakdown in the administration of their health on the basis of past experience.

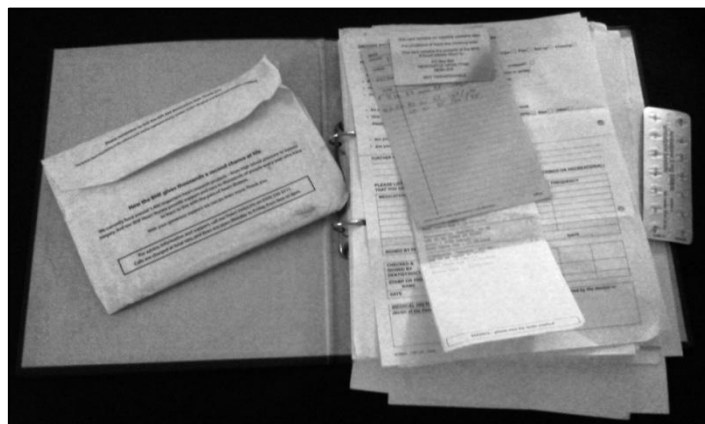


Figure 7.3 Patient's home-made health record

Patients independently developed records, ranging from fairly simple lists and phone numbers, to more elaborate files of past procedures, future appointments and additional records to assist them with personal health goals. Such files could contain a record of dates of any major health-related events, such as the date of a heart attack

or operation; a record of past test results; medication side effects experienced that needed to be reported at the next GP consultation; filed copies of consultant letters to GPs copied to the patient; hospital appointment letters; names and phone numbers for specific hospital departments and consultants' secretaries; details of medication or medical information from non-NHS therapists; a diary to help co-ordinate hospital and GP appointments and memos summarising what to do and who to contact if a test result failed to deliver prior to a consultant appointment.

'I have a calendar plus a file plus two diaries to record appointments, visits and treatments. I record blood pressure and pulse every day. Sometimes I get a bit out of my depth! (Wife of male patient, 78)

On occasion, such collections included details of cardiac exercise classes, physiotherapy exercise leaflets and diet sheets: sometimes information was held to help manage personal health goals, such as units of alcohol drunk or body weight. What was striking was that such collections of information, built up over time, started to approximate a patient health record: to be more precise, such collections could be best described as home-made patient health records, tailored by each patient to his or her own requirements.

'I'm not fussed about seeing my medical records, as I keep my own records, which include my alcohol consumption.' (Male patient, 57)

'I'd advise all heart patients to keep an elementary record of their activities, as they come in very useful.' (Male patient, 70)

The fact that so many patients had individually decided to organise their health-related information using their own, but recognisably similar methods, pointed to a patient need that had perhaps been overlooked, or overshadowed by the debate about electronic health records and access to the data held on them. In the meantime, some patients had arguably invented something more advanced in terms of content and user-friendliness.

CHD patients, like all other chronic disease patients, are privy to large amounts of clinical information about their condition over a number of years and often across a number of clinical specialties. There was clearly a need felt by many of the patients interviewed to organise this information: indeed, two of the seven patients who had not devised a method of managing their health-related correspondence and appointments timetable described how they felt 'overwhelmed' and 'confused' by the sheer volume of written information they had received.

'The problem is dealing with all the pieces of paper – there's masses of the stuff. Yet sometimes I forget to get the information I actually want.' (Male patient, 84)

Interestingly, *none* of the patients interviewed mentioned their home-made health records in the course of being interviewed. The records only came to light when the author noticed that patients would often interrupt the interview to go and look for written documentation, often when a patient wanted to date a specific incident or provide precise details about their medication. Such actions were a good example of the externalisation of tacit patient knowledge, providing an 'acted out' expression of knowledge bound up in the experience of being a long-term chronic disease patient.

The feature common to patients who kept health records was their desire to try and impose greater order on the management of their health. These examples of patient activity around information and knowledge gathering pointed to a tacit understanding by the patient of the kind of information and access to knowledge they personally required in order to co-manage their healthcare in an often chaotic system of hospital administration.

3.1.3 Broader relevance

The individualised, tacit acts of knowledge creation by patients summed up in the act of creating personalised health records were unconsciously creative responses to a problem common to many, but experienced at an individual level. The fact that patients created their own personalised health records was an expression of their tacit knowledge that 'It is necessary to create a personalised system to help overcome problems with non-emergency CHD treatment and to help self-administer healthcare',

a know-how that was developed over the course of repeat visits to GP surgeries and hospital outpatient departments.

This know-how took a more explicit form when patients collected together a written record of everything they had learned it was important for them to know independently of their healthcare professionals. The written record made this knowledge explicit but individualised: patients did not know or think about whether other patients were doing something similar in response to the same experiences; they did not consciously articulate that this practice was generally necessary for those negotiating NHS treatment; they did not even mention it in the course of discussing their healthcare. For the patients concerned, such record-keeping activities formed part of 'what I do to try and keep on top of things'.

Patients collated health records both as records of past treatment and as a guide to future action. Such records often contained practical procedural knowledge gained through patient experience that could short-circuit official routes of healthcare communication. Much of the knowledge acquired by patients concerning the administration of their treatment was time-, place- and person-specific. Individual patient knowledge was confined to a specific hospital, hospital department and often to a specific consultant or GP. Such knowledge was often dependent upon specific staff-patient relationships and sometimes took the form of 'favour' not extended to all patients. So for example, some patients learned how to find out the date of test results and co-ordinate the consultant appointment accordingly, based on the time

actually taken in the past to report diagnostic test results to the required consultant, rather than the time promised in official documentation. Some found out the name and number of the laboratory technician who could actually let them know when a result had been dispatched.

Even where such patient knowledge consisted of explicit knowledge and facts, such as hospital phone numbers and the names of people in the hospital administration system, the knowledge of how to use them to short-circuit the often long-winded and bureaucratic methods used to communicate with patients often contained tacit elements, hard to codify. In its raw form, patient knowledge contained within their home-made records was often not relevant to a broader CHD patient population. However, what is more broadly relevant is the knowledge that many patients needed their own system in order to help them negotiate their long-term care provision: this already suggests strongly that long-term chronic disease management is overly bureaucratic and poorly co-ordinated.

In terms of knowledge management theory and practice, this narrative of events is comparable to Nonaka and Takeuchi's story of how a bread-making technique was identified by an engaged observer from the Matsushita Company and converted into a mechanical method that mimicked a technique unique to the master baker in the course of handmade bread production. As with the master bread-maker, it was the essential technique that needed to be captured by an observer and converted into an idea of potential value both to other CHD patients seeking to improve their experience

of CHD medical treatment and those in the NHS seeking to understand how the long-term management of CHD might be improved. This patient knowledge trajectory is captured in figure 7.4, which shows the stages of knowledge conversion involved in moving from individual tacit patient knowledge to knowledge of organisational value.

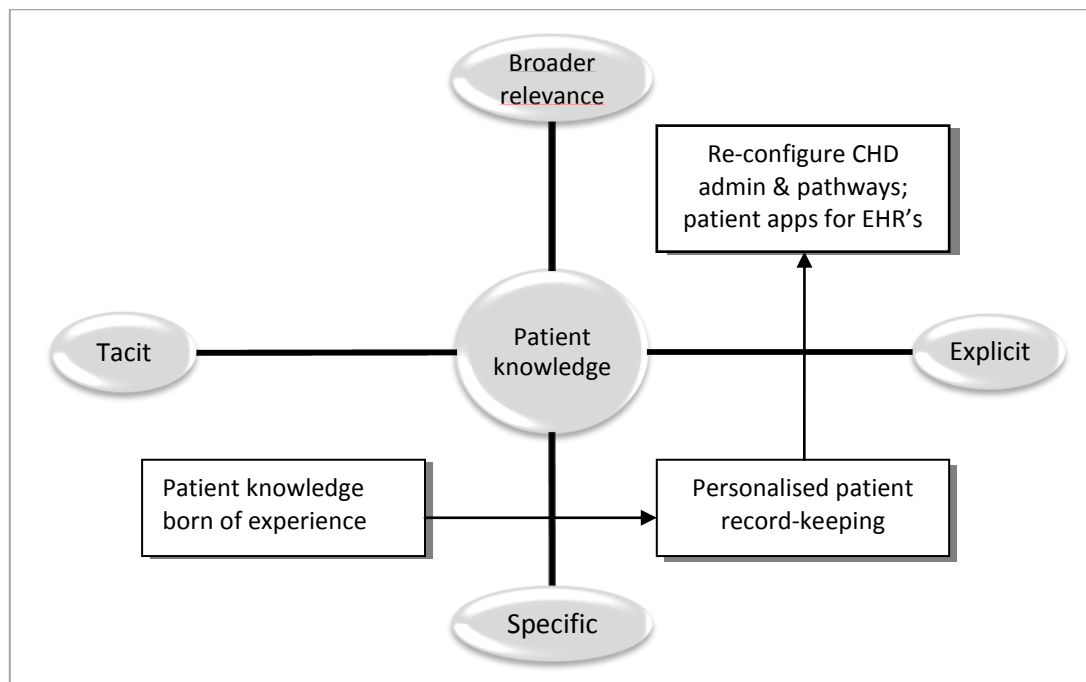


Figure 7.4 Knowledge conversion trajectory: home-made patient health records

Home-made personalised patient health records developed as a consequence of two key facts. Firstly, many patients found it useful to collate health-related information tailored to their specific requirements. Individual patients had an appetite for different amounts of knowledge and information about their condition; beyond this statement of fact, it was not obvious what motivated some patients to create their own health records and not others. For example, it did not seem to correlate to their level of health, as some of the most and some of the least sick patients were active in

collating and managing their personal health information and activity. It may have correlated to the individual's experience of service delivery in the past, but this study did not seek to quantify this in any detail in the patient interviews.

Secondly, such home-made health records were a practical response to the perceived poor health administration that many patients had experienced, providing a back up file of patient information and contact details that could provide the medical and administrative information needed when hospital health records or a letter of referral went missing.

The implicit message contained in such patient activities is that long-term chronic disease management needs to be more patient-centred. It appeared to demand considerable personal effort on the part of many patients just to help manage its administration. A more stream-lined and efficient means of organising patient long-term healthcare would lead to greater patient satisfaction, more efficient use of hospital time and could involve patients in their healthcare in more meaningful ways.

The implicit and explicit individualised patient knowledge contained within the activities surrounding patient record-keeping contains two lessons of possible organisational benefit: firstly, that the current system of non-acute long-term care for CHD patients needs to be made more patient-friendly if greater patient engagement in self-care is to be achieved. Secondly, that CHD patients have already identified in practice the type and range of knowledge and information they currently want or

need: such data should be invaluable to those charged with developing patient-friendly data access portals. In the meantime, and for patients without internet access, the more conscious development of simple paper-based patient-held records that reflect patients' individualised knowledge and information needs might help improve hospital DNA ('Did not attend') rates, as well as improved communication between doctors and chronic disease patients in ways that are known to improve a number of patient health-related outcomes (Ong et al, 1995; Stewart, 1995; Epstein et al, 1993; Kaplan et al, 1989).

3.2 Patient-generated knowledge: knowledge lacked influence over patient behaviour when the outcome was deferred

It emerged during interviews that many patients struggled with their long-term health maintenance⁴. Many patients reported a lack of success in managing their health behaviours, despite being highly motivated about managing their health in general. This concern was probed in the patient interviews and a possible explanation emerged in stages through a series of patient responses set out below.

3.2.1 Self-assessed health management

When asked how well they felt they had managed their own health since being

⁴ Long-term health maintenance is the summary term used here to define actions that can be taken to modify lifestyle-related risk factors known to have a statistically significant effect on morbidity and mortality rates in CHD patients. The main known modifiable risk factors are set out in the 2000 NHS National Service Framework for Coronary Heart Disease, which mentions 'physical activity, diet, alcohol consumption, weight and diabetes'. Health behaviours is the term used to describe a patient's management of these risk factors.

diagnosed with CHD, 28 out of 34 patients responded that they felt they managed very well, well or quite well. To a healthy person, a cardiac patient might well be seen as not healthy, or even be classified as sick. However the cardiac patients interviewed, viewed their chronic but stable health status quite differently:

‘I haven’t come to terms with being ill, although I’m not as fit as I was. Thanks to medication, I’m moderately healthy.’(Male patient, 57)

‘I was ill – but I feel fine now... Ironically, I manage my health better now than ever before.’(Female patient, 68)

3.2.2 Management of lifestyle-related risk factors

Most of the patients interviewed voiced concerns about their ongoing struggle to adhere to the diet, exercise and lifestyle practices known by them to be important methods of stabilising their heart condition and improving their chances of further illness and premature death. It is well known that lifestyle-related risk factors associated with chronic diseases like CHD, such as dietary intake, exercise, drinking and smoking are poorly managed in the population at large and that for many, attempts to manage these factors fail to result in long-term lifestyle changes.

This patient group was arguably more highly motivated to manage modifiable lifestyle risk factors than the population at large: a meta-analysis of adherence studies shows that adherence is positively correlated with a patient’s understanding of the severity of

the disease to be treated (DiMatteo et al, 2007). Most of the study patients had already experienced life-threatening and frightening acute events as a result of serious heart disease - 13 had suffered heart attacks, 3 had had strokes, 10 suffered from acute angina, 4 from the effects of heart failure. It might therefore have been expected that such study patients, who were all highly knowledgeable about the risk factors associated with secondary CHD management, might be more conscious of the disease threat posed by their illnesses and therefore more motivated to modify those risk factors than their less sick peers. Patients were therefore invited to examine the extent to which their knowledge coupled with their past experience had combined to influence their behaviour in relation to known lifestyle-related risk factors.

3.2.3 Adherence to medication

Adherence to taking prescribed medication is a measurable guide to how committed a patient is to following the medical advice they receive from their GP or hospital consultant. 30 out of 34 patients stated that they adhered to the dosage and frequency of CHD medication advised by their GP or specialist consultant; 2 reported accidentally forgetting to take some of their medication on a fairly regular basis; 1 patient had discontinued taking aspirin against his GP's advice; 1 patient had discontinued using statins, but had eventually been persuaded back onto them by his GP. Patients were largely willing to adhere to medication, even where that medication caused some degree of discomfort: they either accepted the side effects or had the medication changed.

'I'm constantly tired and it gives me an upset stomach, but I believe the doctor has my best interests at heart.' (Male patient, 53)

'I feel tired after I take my pill, but I know it's important to keep taking them.' (Male patient, 55)

'Some of the blood pressure pills gave me headaches, so I had them changed. I always take them though.' (Female patient, 77)

'The tablets make me tired – do they bring my blood pressure down? They certainly make me sweat, but I'm told I'll have to take them for the rest of my life.' (Male patient, 57)

There seemed to be a strong association in the mind of each patient between the health-preserving effect of the medication and the necessity of taking it that helped to motivate patient drug adherence.

World Health Organisation estimates suggest that about 50% of patients with chronic diseases living in developed countries adhere to treatment: poor patient adherence to medication is often associated with treatments that take a long time and have side effects (WHO, 2008). Drugs used to control CHD usually need to be taken daily for the rest of a patient's life and can cause unpleasant side effects, including extreme fatigue, water retention and swollen legs, cramps and indigestion. In spite of these factors,

this patient group showed an extremely high level of adherence. Self-reporting may have led to an overstated level of adherence to medication, but the answers were plausible given the degree of motivation generally in evidence. The high levels of medication adherence reported did not, however, predict patient responses regarding adherence to the health behaviours promoted and advised by their GPs and consultants.

3.2.4 Adherence to lifestyle-related health advice

When discussing what aspects of managing CHD they personally had most difficulty with, 21 out of 34 patients declared they had a problem with either maintaining a healthy diet, or taking the amount of recommended exercise, or both.

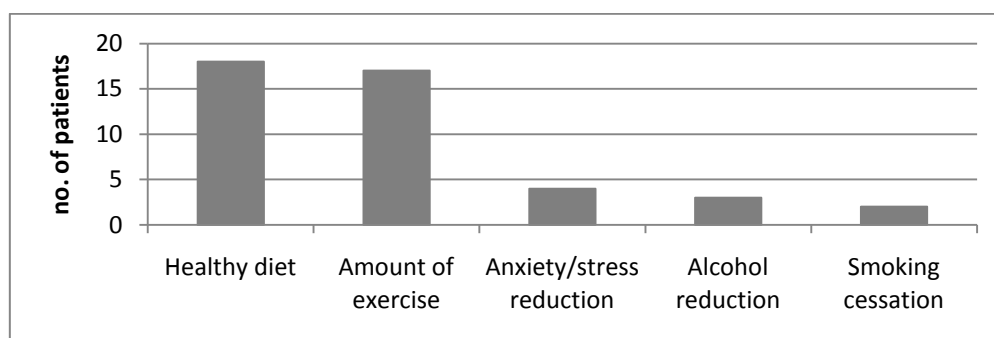


Figure 7.5 Self-reported problems with long-term health maintenance

Other problems reported were difficulties managing stress reduction, problems reducing alcohol intake and smoking cessation. In total, 26 out of 34 patients declared that they had problems managing one or more of the known modifiable risk factors associated with CHD.

'The cardiologist told me to lose weight and exercise. I went to the gym and bought an exercise bike – I went from 16 to 13 and a half stone. Now I'm back up to 17 stone 7....I know I should eat less and exercise more' (Male patient, 70)

'I did worry about my weight – it was hammered into me that it mattered, but I couldn't lose weight.' (Male patient, 79)

'The doctor said I was built for comfort, not for speed and I should lose weight – but how, when my knee ligament gives out?' (Male patient, 53)

'They all say "If you could stop smoking cigars."...I've stopped 35 times. Now I'm at a stage where I'm not even trying to stop.' (Male patient, 77)

3.2.5 The paradox of lifestyle modification: personal or medical issue?

Interviews revealed a paradoxical attitude among many patients on the matter of lifestyle modification. All understood that managing lifestyle-related risk factors was an important aspect of managing their health: most had received some form of medical advice about modifying their health behaviours through their GPs, practice nurses or through a cardiac rehabilitation programme. Most patients described experiencing varying degrees of frustration in the course of trying to make the long-lasting changes to their health behaviours advised by healthcare experts.

Over half the patients interviewed mentioned personal difficulties with maintaining satisfactory levels of exercise, such as one hour's walking every day or the required dietary restrictions associated with heart health, such as eating lean meat and drastically reducing salt and saturated fat intake. Despite its medical *importance*, patients were much less clear as to whether lifestyle modification was a medical matter: many were of the opinion that managing their health behaviours was a private, personal matter, rather than an aspect of chronic disease management that might require medical help or intervention. Even though discussion had revealed just how much they struggled, and often failed, to manage their health behaviours to their own satisfaction, many patients voiced the view that this was a failure of personal responsibility, rather than a health-related problem that, as with medication, required medical monitoring and advice.

'It annoys me to be fat – it's my fault and nobody else's.' (Male patient, 88)

'I receive no GP help with my weight problem – he takes the sensible view that it's up to me.' (Male patient, 57)

'It's not really a medical problem, so I don't feel I should be taking up time in a doctor's surgery.' (Male patient, 62)

(of his GP) *'I don't want to pass responsibility to him for how I live my life.'* (Male patient, 77)

'In my own head I'm five stone less. I'll sort it - I've noticed that Alli in the chemist – maybe I'll try that.' (Male, 68)

'I was offered a diet sheet, but I refused it...I know what to do....It's my fault, so I should sort it out myself... I don't expect a doctor to help me out. I need to sort this out (patting stomach) before I go back to the doctor's about my pills not working properly.' (Male patient, 88)

'I don't need something to help me do what I know I ought to be doing anyway... It's not a medical issue' (Male patient, 57)

There was a noticeable difference of opinion among patients on this topic: of the 21 patients who reported having problems with managing health behaviours, 12 felt it was their responsibility alone to try and manage their long-term health maintenance, whereas 9 patients said they would actively welcome an expansion of services to help them better manage their lifestyles, although few were clear about exactly what kind of intervention might help. Certainly, none of the patients felt that they required help in terms of additional *information* on diet and exercise, as they did not lack the necessary knowledge about what they ought to do.

'When I told my GP I was having real problems keeping my weight down, he referred me to the practice nutritionist. Well, it was pretty useless - she didn't tell me anything I didn't already know.' (Female patient, 68)

'I don't need classes to stay on the straight and narrow – that's too much like AA – maybe I'd benefit from a reminder to deal with exercise.' (Male patient, 56)

'It would be nice to have someone at the end of a phone.' (Male patient, 53)

In this regard, the patients interviewed reflected the more widely held conflicting views about the management of health behaviours. Even though it is widely understood that poor health behaviours correlate strongly with the development and poor management of chronic disease, a glance through the popular and broadsheet press shows that there are widely conflicting views as to whether the management of such health behaviours, such as obesity, alcohol intake and sedentary behaviour should be regarded as a private exercise in self-control or a health concern that necessitates incentivised or coercive medical intervention.

3.2.6 Why does patient knowledge have so little influence on long-term health behaviours?

Health behaviours often prove impervious to long-term change in the light of knowledge alone: the current escalation in the incidence of obesity in the UK population is not the result of increasing ignorance about its health effects. As discussed in the literature review (chapter 3, section 2.1), if anything, we now know more than previous generations about how to live healthily.

Over and again, in different ways, the patients interviewed expressed the disconnection between what they *knew* about the dangers of poor health behaviours and their own subsequent *practice*. Despite a high level of knowledge about health behaviours, 28 out of 34 patients expressed their frustration that this knowledge failed to help them modify poor health behaviours over the long term.

At the same time, most patients *had* learned to apply the precautionary principle to activities where there was no time lapse between an activity and its immediate health effect.

'When you see a bus coming, it's better to let it go than it is to get all stressed about running for it. Better to be late than risk having a heart attack.' (Male patient, 75)

'I take charge on days when my heart isn't working well – I cancel supper dates, I don't go out in humid weather. I've had to learn to say no when I start to feel unwell, instead of soldiering on.' (Female patient, 68)

The same precautionary behaviour was much less in evidence when patients described the extent to which possible health effects *set at some unknowable point in the future* generally failed to determine many of their immediate health-related decisions relating to such behaviours as diet, exercise or alcohol intake. Patients expressed in their own ways why their knowledge did not act as a guide to their actions when it came to long-term health maintenance:

'I've taken up exercise so many times, and then I stop and then it's hard to get going again. Why do I do that? I know it's good for me, but knowing that isn't enough to get me to the gym. ' (Female patient, 58)

'Trouble is, I like smoking – I know it's bad for me, but I really enjoy it and it relaxes me.' (Female patient, 75)

'It's hard to stop eating fatty things like cheese just because you know it might clog your arteries and give you a heart attack – after all, you might have a heart attack anyway... either way, you'll never really know what really caused it....' (Male patient, 56)

In a range of different ways, patients described their difficulties in relinquishing personal pleasures in the present in the interests of avoiding a possible negative consequence at some point in the future – a difficulty that can be summarised as the problematic relationship between a cause and deferred health effect. The connection between health behaviours and future health outcomes was known and well understood, but less strongly 'felt'; or, to put it another way, the lure of unhealthy behaviours in the present was often stronger than the dissuasive effect of understanding the long-term and cumulative consequences of those actions.

3.2.7 Broader Relevance

There are two findings that flow from the patient data on health behaviours. Firstly, as much of the behavioural literature confirms (Davison et al, 1991; Gabhainn et al, 1999; Narevic et al, 2002; Angus et al, 2005), patient knowledge did *not* appear to play a decisive role in determining long-term health behaviours. Secondly, it appeared to be the unknowable time lag between the cause (the patient's health behaviour), and the effect (the patient's morbidity and mortality outcomes), that reduced the influence of patient knowledge on their health-related actions.

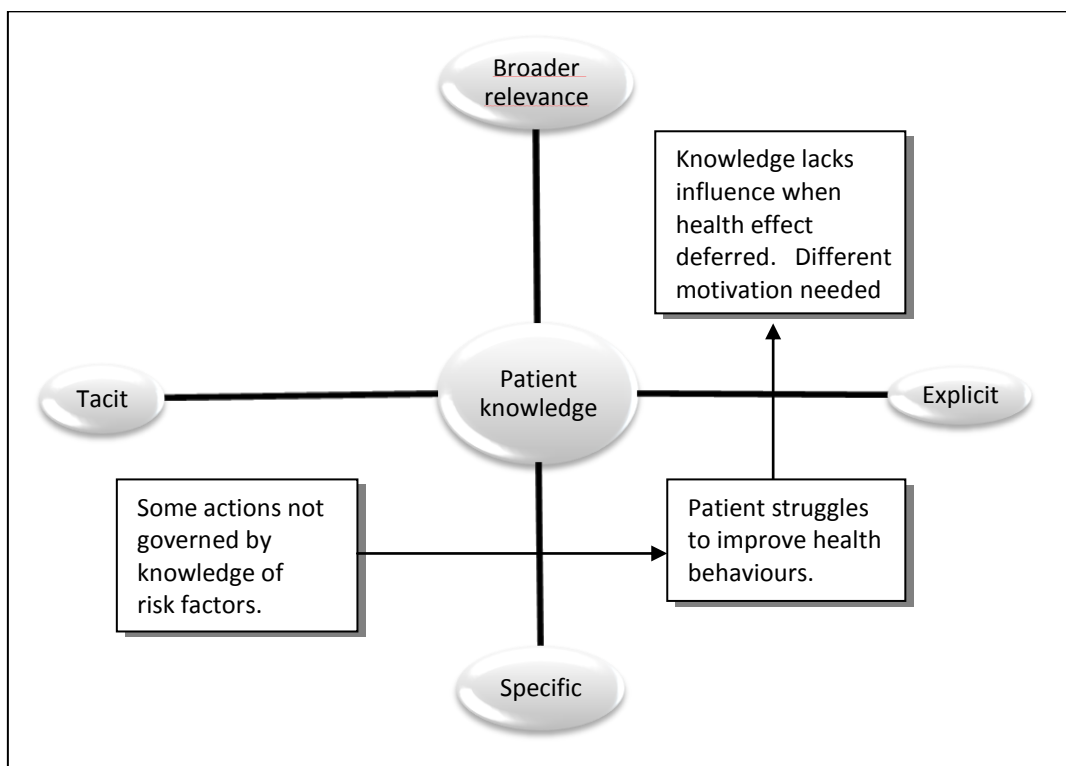


Figure 7.6 Knowledge conversion trajectory: the failure of patient knowledge to influence patient behaviour when health effect deferred

The figure above depicts how patients are, at an individual level, quite explicit about the fact that they cannot manage to improve their health behaviours in the long term to their own satisfaction. When asked to talk about what aspects of CHD healthcare they are good at, the patients in different ways, draw an important distinction between those aspects of healthcare that they manage successfully and those that they do not, exemplifying a kind of tacit knowledge about their health behaviours that is not fully articulated.

What these self-healthcare examples show is that the aspects that patients manage well, such as resting more readily when they are tired, or not running for buses, or devising methods to make sure they take their medication diligently, sit in contrast to those aspects of self-healthcare they feel they cannot manage well, which seem to be characterised by the unknown time gap between the health-related activity and its negative health effect.

After a number of interviews, the author/observer started to notice this pattern in the account of many of the interviewees and felt able to abstract a general statement from it that might apply more broadly: namely, that patient knowledge lacked influence over health behaviours where there was a time lapse between behaviour and health effect. For this reason, forms of patient motivation are needed that do not rely on factual health knowledge acting as a deterrent to poor health behaviours.

Is it right to say that these findings were generated by patients? The primary knowledge belongs to the patients, but in a largely tacit and experiential form. In discussion, a conclusion was drawn by successive patients in different ways at an individual level when they tried to explain their own weakness in relation to managing their health behaviours. This needed to be drawn out and rendered explicit by an engaged individual.

Once drawn out, this individualised patient knowledge acquired a broader significance to the observer when it appeared to explain an experience common to many of the patients interviewed. Its implications for organisational learning are obvious: health education is unlikely to resolve problems with health maintenance in the long term. Other forms of behavioural, as well as medical and surgical interventions need to be considered.

4. SUMMARY OF MAIN RESULTS

There were 2 main findings to the research question: do patients, in the course of managing their CHD, generate knowledge about their condition and its treatment?

4.1 The development by patients of home-made health records revealed their tacit, individualised knowledge of the informal workings of their local NHS hospitals and surgeries for managing non-acute treatment for CHD patients. It also revealed their understanding of the need to create a more personalised administration system for

managing their healthcare, to run in parallel with the formal NHS healthcare administration system.

At a more explicit level, patients generated their own home-made health records as a means of managing the information associated with their healthcare and as a guide to rendering their dealings with health providers more productive and efficient.

4.2 Many patients described difficulties with their long-term health behaviours, where their degree of knowledge about *how* to manage health behaviours appeared to play little role in determining their actions. It seems that patient knowledge lacks influence over patient behaviour, when the outcome of that behaviour is deferred to an unknown point in the future.

4.3 A model was developed to help explain how patient knowledge can be converted into organisational knowledge. The model also helps to explain why patient knowledge is not always immediately apparent or easy to capture in a form that has organisational value.

CHAPTER 8| RESULTS: THE GP SURVEY

1. INTRODUCTION

This chapter reports the results of a questionnaire sent to GPs in Camden PCT. The results are grouped in response to the study's research questions concerning patient knowledge-seeking and knowledge creation. A brief profile of respondents is also provided.

In relation to patient knowledge-seeking, the chapter records GP perspectives on the barriers to effective CHD management, the interventions offered by GPs to assist CHD patients with weight reduction and GP perspectives on patient non-compliance. GP attitudes to patient self-care are also reported, as are GP responses to patient use of alternative medicine. In relation to patient knowledge-seeking, GP responses are reported concerning how often, and in what ways GPs seek any kind of feedback from CHD patients about their treatment.

2. THE QUESTIONNAIRE

A number of issues emerged in the course of the patient interviews that prompted general questions about GP practice: to this end, an online questionnaire was developed (appendix G). A copy of the questionnaire was sent to all 43 GP practices in Camden PCT, with the request that one GP per surgery respond to the questions.

Doctors from 16 practices in Camden PCT replied. The replies cannot be taken as representative of the views of all GPs in Camden or more generally, as they lack the statistical power to do so; however, the comments and opinions of the GPs who responded provide a useful indication of the spread of GP attitudes regarding some of the matters of concern to the patients interviewed.

All responses were anonymised prior to data analysis. The majority of GPs who filled in the questionnaire were between the ages of 35 and 49; 10 GP respondents were female and 6 were male.

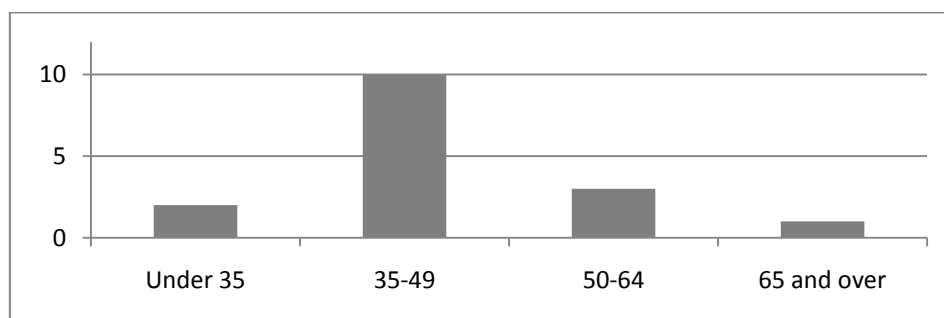


Figure 8.1 Age distribution of GP respondents

It is worth noting that GPs were asked to respond to questions concerning *all* their patients with CHD. The patients concerned will include the type of highly motivated patient most likely to respond to a study such as this one: however, a GP list is also likely to contain a much greater spread of CHD patient types, ranging from most to least motivated, so the types of patients covered by their response will have included patients such as those in this study, but not exclusively.

3. RESULTS

For the purposes of this study, the results of the GP questionnaire are reported as they relate to the two research questions.

3.1 Patient knowledge-seeking

Lifestyle-related risk factors such as diet, exercise and weight management had proved to be major concerns to patients interviewed, and their satisfactory management had proved to be resistant to the influence of patient knowledge of the issues involved. GPs were asked a number of related questions, as well as more general questions on GP attitudes to CHD management and patient responses to treatment.

3.1.1. GP perspectives on patient CHD management

When asked to identify the barriers to effective CHD management which they had experienced (figure 8.2), GP responses focused on three distinct themes: patient motivation and compliance; lack of GP time; and inadequate staff training; 2 GPs also identified broader systemic problems relating to NHS targets.

By far the most common barrier to effective CHD management reported by GPs was lack of patient motivation, described variously as *'reluctant and careless patients'*, *'patient non-compliance'* and *'patients not motivated'*.

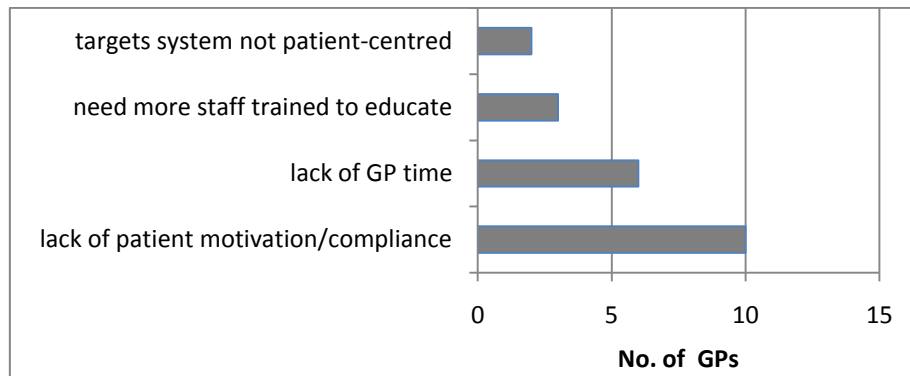


Figure 8.2 GP-identified barriers to effective CHD management

Lack of GP time was cited in 6 cases, indicating that the GP felt that an increase in time spent communicating with each CHD patient would in itself result in better CHD self-management. Similar beliefs lay behind the stated need for additional staff trained in dispensing patient information on diet or exercise. Finally, two GPs identified systemic problems as barriers, stating that the NHS targets system did not encourage patient-centred medical treatment.

It was interesting to note that there was no mention of the broader problems of healthcare administration and the problems identified by CHD patients concerning the management and administration of chronic, non-acute healthcare across clinical disciplines and across primary and secondary care, despite this featuring so emphatically among patients in the study.

3.1.2 Weight management is a problem for the GP as well as the patient

Previous studies have shown a general lack of optimism among GPs and practice nurses about encouraging patients to improve their health behaviours, based on their

experience of poor patient response (Steptoe et al, 1999; Harris Interactive, 2009). Such attitudes were reflected in the GP questionnaire responses.

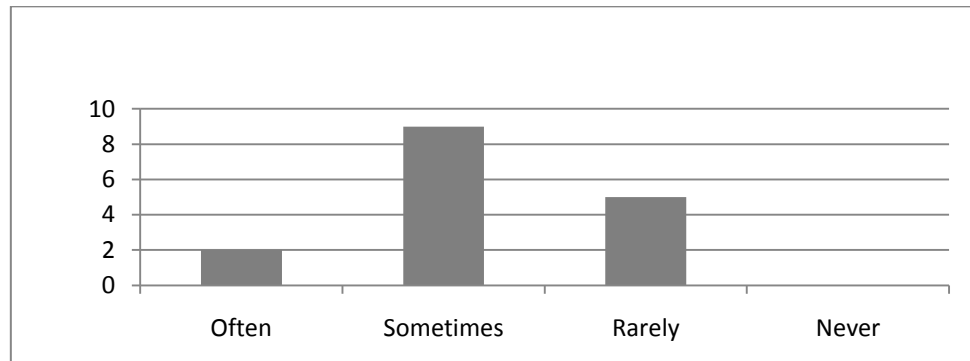


Figure 8.3 Do overweight CHD patients request help with weight reduction?

All 16 GPs who replied stated that they did ask overweight CHD patients to try and reduce their weight: fewer reported that these same patients actively sought their help. This result meshes with the patient study finding that many patients tend to regard the management of weight loss and other health behaviours as a non-medical issue which they do not expect GPs to help them with. Patients may seek advice and support elsewhere, perhaps among friends and family, as did many of the patients interviewed in this study. It may also be that some patients give up trying to regulate their weight and do not seek to discuss it with their GP for this reason.

3.1.3 GP Interventions

When asked what kind of assistance with weight reduction they offered overweight CHD patients, the most common GP response was that patients were supplied with diet sheets or dietary and lifestyle advice: a review of the literature showed that there

was some conflict about the impact of patient knowledge on patient behaviours, although there was agreement among behavioural psychologists that on matters of gratification versus longer term goals, issues such as weight management were not amenable to regulation based on the individual knowing what they *ought* to do (Herrnstein 1996; Rachlin, 1995; Baumeister et al 1996). 6 GPs mentioned exercise referral, as patients can now be given free vouchers to attend exercise classes at their local gym for a limited period, although studies show that this has little long-term impact (Brownell, 2010; Drinkwater, 2007).

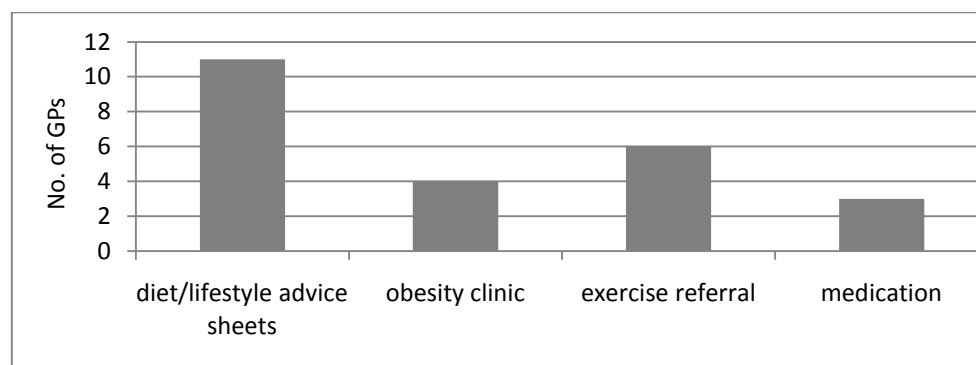


Figure 8.4 Do you offer overweight CHD patients weight reduction aids?

Referral to a nurse-led obesity clinic was mentioned by four out of sixteen GPs, and medication such as Orlistat was mentioned by three GPs, but only as something they would consider in extremis, even though such medication is available without prescription in pharmacies for anyone with a BMI of 28 or over.

In terms of the study patients, none had been offered a clinic referral or medication, although many had been offered diet information sheets.

3.1.4 Patient non-compliance

Patient non-compliance was clearly a problem for the majority of GP respondents, with 13 out of 15 GPs reporting that their CHD patients sometimes or often disagreed with or disregarded the proposed treatment for managing their condition.

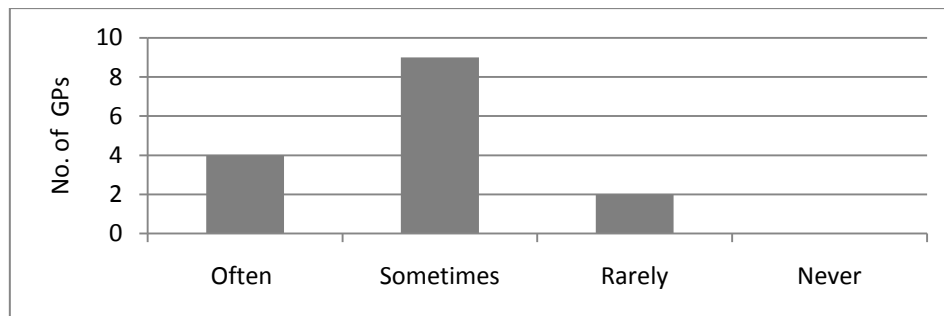


Figure 8.5 Do your CHD patients ever disagree with or disregard the treatment you propose for managing their condition?

Interestingly, the areas of non-compliance were twofold and common to all GP respondents: firstly, almost all GPs reported a problem with patient refusal to take medication as prescribed, especially statins and beta blockers. Secondly, GPs reported non-compliance in the area of health behaviours - smoking, weight management, diet and exercise.

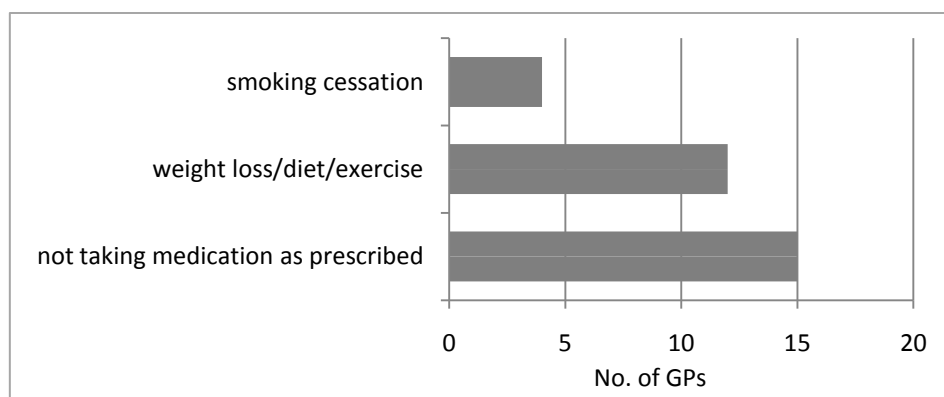


Figure 8.6 Areas of treatment CHD patients least likely to comply with

The patient study indicated that two patients sometimes *forgot* to take their medication on a regular basis, but the patients interviewed did not report refusing to adhere to prescribed medication, despite many patients taking more than 5 types of medication per day. This under-reporting relative to the GP response suggests that patients in this study are probably more highly motivated than the general CHD population; it seems unlikely they were lying about their medication adherence, given their honesty about health maintenance generally.

Ongoing problems with health behaviours loomed large for many of the study patients, despite their high motivation, and this problem is also reflected in the GP responses. In addition to reporting that overweight patients often did not seek their help, 12 GPs reported that they experienced problems with compliance when it came to weight reduction. The patient study revealed that it would be wrong to assume that patient non-compliance is necessarily a result of patient nonchalance or conscious refusal to adhere to medical advice: it can also indicate a failure of motivation despite a conscious desire to comply.

3.1.5 Patient self-care

When asked about types of self-management they already encouraged among their CHD patients, 10 GPs reported that they encouraged home blood pressure checks; at the same time, 2 GPs reported actively discouraging home blood pressure checks on the grounds that '*there is no evidence that it helps*', although there is recent research evidence to the contrary (McManus et al, 2010; Agarwal et al, 2011). Encouraging

patient health maintenance was mentioned three times, with GPs reporting that they actively encouraged diet and exercise.

Camden PCT has been encouraging its GPs to promote the Expert Patient Programme as well as some telehealth initiatives to patients with longstanding conditions. It is interesting to note that, despite such ‘top down’ promotion, both initiatives are mentioned by only 1 out of 16 GPs. It is not possible to know from these results whether this is due to lack of GP knowledge of the initiatives, or GP indifference or resistance to these particular forms of patient self-management.

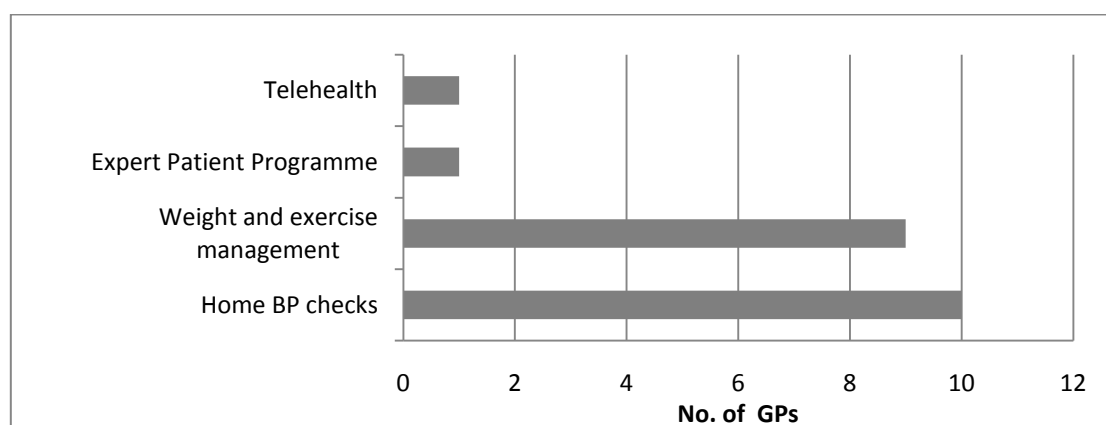


Figure 8.7 Do you encourage self-management for CHD patients?

When asked whether they felt that an increased emphasis on patient self-management would benefit CHD patient health, the majority of GP respondents thought it would help: *‘Patients will take more responsibility for their healthcare and rely less on healthcare professionals’*. However, 3 GPs were unsure it would benefit patient health and 2 GPs felt it would not benefit patients: *‘They (patients) know what to do, but don’t always do it’*.

When asked specifically what aspects of self-care patients need more help with, the majority of GP respondents thought that patients needed help with managing health behaviours. There were also 2 mentions of the need for help with drug compliance and 1 mention of the need for patient education about managing CHD.

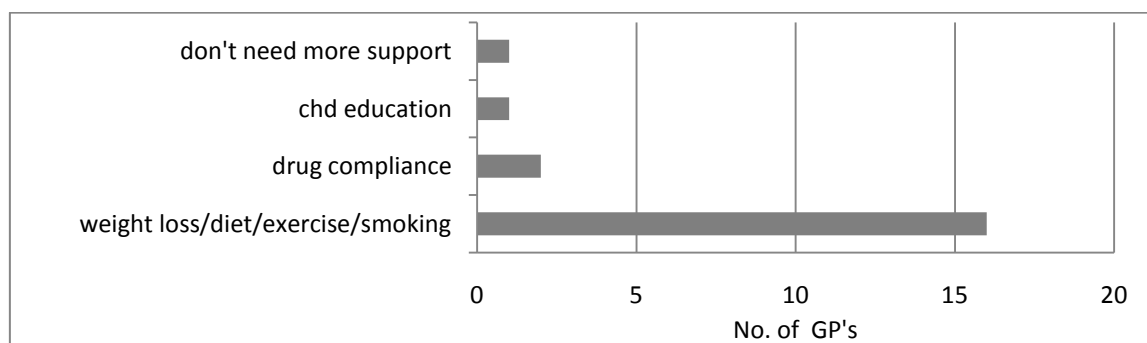


Figure 8.8 Do CHD patients need additional self-care support?

The 'polypill' or all-in-one tablet was mentioned as a possible solution to drug compliance by one GP. Another felt that patients did not require further supportive interventions, as '*patient healthcare should be their own concern*'.

Faith in the power of knowledge to change behaviours was much in evidence in the GP responses to what they thought might help CHD patients to improve their self-care. Most mentioned the need for more patient education, despite so much evidence pointing to the relative ineffectiveness of improving knowledge as a means of altering patient health behaviours in the long term, as well as evidence that the population is generally cognisant of the modifiable risk factors governing CHD (discussed in Chapter 3, section 4.9).

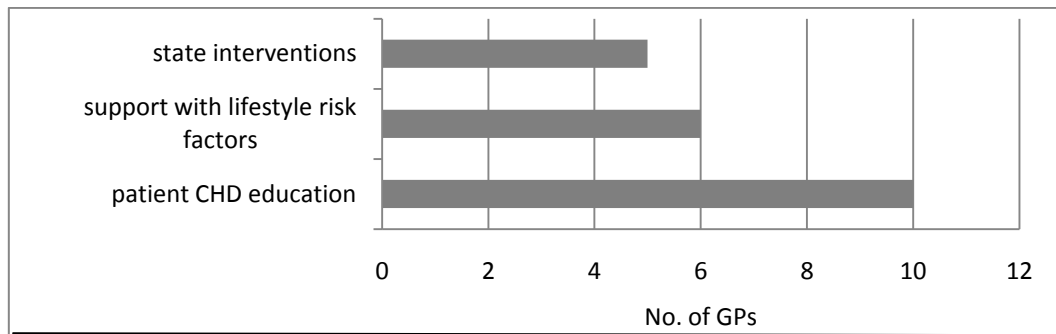


Figure 8.9 What might help patients improve their own management of CHD?

Interestingly, 6 GPs mentioned the need to provide patient motivation and support with lifestyle risk factors such as diet and exercise: this ties in closely with the views expressed by many of the patients interviewed. 5 GPs felt that broader social influences would need to be brought to bear on patient behaviours and suggested population level interventions. Of these, 3 suggested the need to change how people lived so they could adopt healthier lifestyles, advocating food labelling and free prescriptions for drugs to manage hypertension and cholesterol. The 2 other GPs suggested the introduction of more punitive public health social policies, in the form of a complete smoking ban or individual patient financial and health treatment penalties to discourage poor lifestyle behaviours.

3.1.6 Alternative medicine receives mixed GP response

All GP respondents reported being aware that their CHD patients often used alternative therapies or treatments that had not been prescribed by them, and reported feeling, for the most part, that it was a valid patient choice as long as they still adhered to prescribed treatments. Only half of GPs mentioned that they felt it

necessary to point out the lack of scientific evidence concerning the efficacy of alternative treatments, or mention possible risks or interactions.

3.2 Patient knowledge creation

When asked about patient feedback, GP questionnaire responses were noticeably less informative than on other matters, although the topic also provoked the broadest range of responses. Most GP respondents reported seeing data on patient satisfaction or patient feedback about once a year.

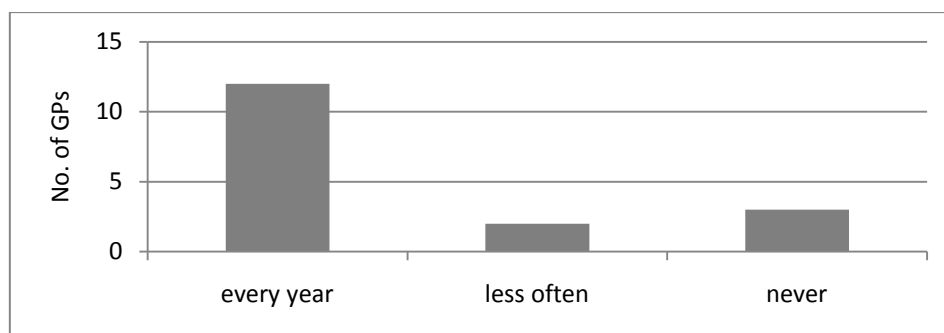


Figure 8.10 How often do you receive data on CHD patient satisfaction/feedback?

A survey of GP patients by surgery is administered annually by Ipsos Mori for the Department of Health on a quarterly basis, so it is interesting to note that the availability of such information does not mean that every GP takes note of it.

When asked if there was any system for feeding back patient suggestions in their surgery, it was interesting to note that only 4 GPs reported the existence of a patient

participation group at their surgery, an approach currently encouraged by the BMA as a means of consulting directly with patient representatives.

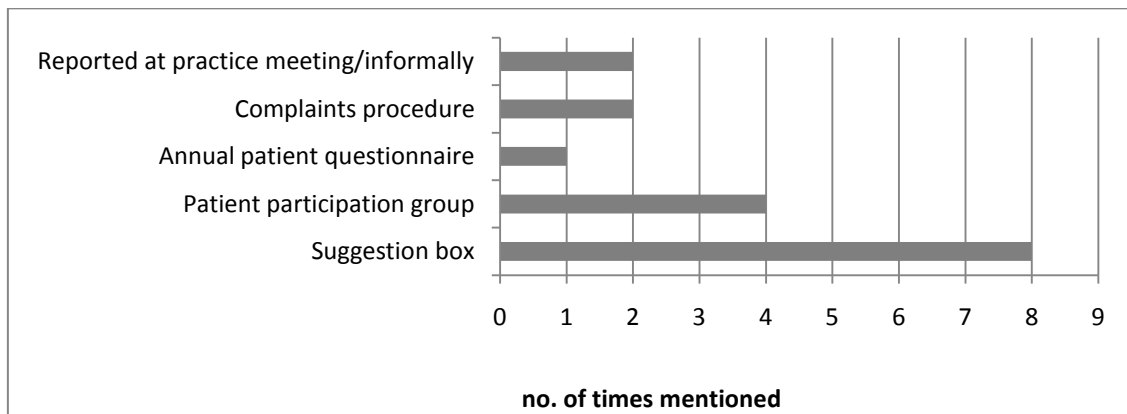


Figure 8.11 Is there a system for feeding back patient suggestions for changes or improvements to their care to your practice manager, PCT, or anyone else?

A further 4 GPs stated that there was no real system as such in place in their surgery: 8 reported that there was a surgery suggestion box that patients could use if they wished; a few mentioned the possibility of verbal reports about patient feedback at practice meetings. 2 GPs cited the official complaints procedure as the primary vehicle for patient feedback.

GP responses suggest that the idea of increased self-management or active patient participation for people with chronic CHD is very much in its infancy, at both the level of service delivery and actively involving patients in their own treatment regimen.

4. SUMMARY

4.1 The results of the GP questionnaire provide some indication of GP attitudes and practice in the Camden area and surrounds in relation to some of the patient concerns identified in the study. In terms of patient knowledge-seeking, most of the GPs questioned identified poor patient motivation and non-compliance as a major barrier to effective CHD management: even so, most GPs still believed that more patient education might help, although half of GP respondents did report the need for more patient motivation and support when it came to managing health behaviours. A smaller number saw the need for state intervention to address the broader social determinants of health or incentivise healthy behaviours in the general population.

4.2 GPs reported CHD patient non-compliance to be a particular problem in terms of medication non-compliance and with poor management of health behaviours. Medication non-compliance scarcely featured in the patient survey, perhaps indicating a higher degree of motivation among the patients who opted in to the study than is usual among CHD patients: but problems managing health behaviours also featured strongly in the patient interviews.

4.3 In terms of interventions to help patients manage their weight problems, there was still a heavy GP emphasis on patient education, in the form of diet sheets and clinics, despite evidence that improving patient education and knowledge shows little evidence of being effective in the long term. There were some mentions of exercise referral and the use of Orlistat to be used in extremis.

4.4 GPs reported that overweight patients do not always seek help from them and are often not compliant when it comes to weight reduction. The overall message was that GPs identify patient obesity as a medical problem, but their approaches to treating it appeared relatively tentative, often using methods known to have little or no effectiveness.

4.5 Attitudes to patient self-care among the GP respondents indicated that this Department of Health imperative has not made a big impact on their GP practice on the ground: a few of these GPs reported that their surgeries had patient participation groups, but there was little evidence of a systematic approach to involving individual patients in the co-management of their own health. In addition, patient feedback regarding their existing treatment did not seem to feature highly as a clinical priority, and tied in with lack of time which was cited as one of the major barriers to effective CHD management.

4.6 The GP respondents were generally aware that many of their CHD patients also took alternative medicines, but there was a range of opinion about how GPs should respond, from ensuring that such treatments did not interact with CHD medication to actively advising about the lack of evidence of the medical efficacy behind many types of alternative treatments.

4.7 It was interesting to note that patient difficulties associated with the administration of non-acute CHD treatment, especially in hospital outpatient clinics,

did not feature as a perceived problem among GPs, despite featuring so heavily among CHD patients interviewed. This suggests that GPs, despite being responsible for arranging patient care across primary and secondary care, appear to be unaware of the extent of the problems many patients face in terms of chaotic administration.

CHAPTER 9 | DISCUSSION AND CONCLUSION

1. INTRODUCTION

This chapter interprets the study findings in light of the existing literature. First, section 2 below considers some of the limitations of the present research which should be borne in mind. In sections 3 and 4, the results associated with each of the two research questions are contextualised and discussed, as are any broader implications. Suggestions are made for future work. Section 5 concludes the discussion and the thesis.

2. LIMITATIONS

2.1 Transferability of findings: the patient cohort

In qualitative research, external validity is measured by the extent to which research results are transferable to different populations with similar key characteristics – in this case, the characteristic of being a patient with coronary heart disease (Lincoln et al, 1986). It is necessary to consider some of the features of this research which may have impacted on any such transferability.

The requirements set down by Camden's Research Ethics Committee meant that patients had to read a detailed study information sheet and return a stamped addressed envelope containing their details in order to opt into the study. This is likely to have deterred patients with poor reading skills, as well as those who were unable to

read English well as a second language, which means that the study did not examine the issue of poor reading skills as it might specifically relate to patient knowledge-seeking .

It was evident upon interviewing those who had opted into the interview process that participants were almost exclusively highly motivated, medically compliant patients, very few of whom exhibited the problems of failing to, or refusing to take their medication as prescribed, despite this being a problem identified both in the literature and by GPs in the study questionnaire. In terms of the study results, this suggests that patient who do not adhere to medical advice are not well represented in the study.

2.2 Hypothetical nature of the findings

Although many qualitative studies seek to assert the generalisability of their findings, study results arising out of a qualitative study can only be said to hold true with certainty for the study participants. Beyond this immediate group, findings have the status of hypotheses which require further testing on different, or larger and statistically representative CHD patient groups, before one can be sure of their incidence or significance in the general CHD patient population. It is in this spirit that the discussion below sets out the recommendations that flow from the study findings; it is also to this end that areas of research are identified that could help further illuminate these findings.

3. DISCUSSION OF RESULTS RELATING TO THE FIRST RESEARCH QUESTION

3.1 Result 1

The patients studied sought three different types of knowledge from different knowledge sources: firstly, expert knowledge from GPs and consultants; secondly, personalised practical knowledge from nurse specialists and cardiac trainers; thirdly, 'folk' or common sense knowledge from close friends and family and other patients.

Discussion

This result is a new contribution to the existing literature. In reality, patient knowledge-seeking may not be quite as neat as it appears when summarised in this way, but the patients interviewed did, in general, make clear distinctions about what type of knowledge and information they valued, and from what source. It is interesting to note that the sources most highly valued by the patient interviewees all derived from direct human interaction: patients generally trusted the results of knowledge derived through personal interaction more than any interactive website or printed literature.

Doctors and nurses

There is little remarkable about patients seeking expert medical knowledge from medical experts. It is more interesting that the views of such medical experts are deemed less relevant when patients require health knowledge regarding the more

practical aspects of living with CHD in everyday life, rather than technical surgical skills or in-depth biomedical expertise. For this, patients expressed a preference for nurse specialists and cardiac trainers: patients felt these health professionals had both the time and the relevant expertise required to advise them on managing these more practical aspects of chronic disease management.

Nearest and dearest

The findings on the role of friends and family in patient knowledge-seeking require more explanation. Friends and family were the people most likely to share the values and outlook of the patient, and appeared to provide knowledge and information about CHD to patients on the basis of experience, observed experience, or relayed from another source they found credible or interesting. The patient's evaluation of the quality of the information and knowledge provided by friend or family appeared to relate closely to the patient's level of trust in the friend or family member, rather than their medical expertise – indeed, few patients interviewed had friends *with* qualified medical expertise. There is very little evaluation in the literature of why patients seek knowledge from close friends and family. The author found only one mention in the existing literature: interestingly, this refers en passant to the fact that patients interviewed in a study on health beliefs among post-coronary patients appeared to give more weight to information provided by family and friends than by health professionals (Murray, 1989).

Friends or family members, as well as other patients were often responsible for the kind of 'tried and trusted' health advice that can best be summed up as 'What worked

for me or someone I know'. This seemed to replace recourse to 'tried and tested' expert medical expertise as an approach to say, exercise, dealing with medication side effects, or pain management. Patient trust was based, not on their ability to judge the quality of the medical information received from family or friends, but rather through proxy judgements – for example, based on the extent to which the friend or family member - often a partner, son or daughter - was known to *care* about the patient and his or her health.

Close friends and family are likely to share a patient's social identity, feel empathy and engender trust in a patient in ways that health professionals often cannot. In trying to understand how social networks affect the generation and transmission of knowledge, cognitive anthropologists such as Roy d'Andrade and Naomi Quinn use the term 'folk knowledge' to describe the implicit, culturally shared ways that people understand the world around them. Folk knowledge thus understood often takes the form of experience or practical wisdom, and is viewed by many anthropologists and behaviourists as a powerful motivator of human activity among those who share the same outlook, as it is based on cultural models and ways of understanding the world that have been internalised by that social group. Folk knowledge thus transmits relatively effortlessly through each individual's social network: it can also vary greatly between individuals in different social networks, for example, someone brought up in a household that used homeopathic remedies is more likely to continue to use them as an adult than someone brought up in a medic's household. Behavioural theory advances a similar claim, stating that individual behaviour – as well as the individual's

capacity to change – is predicated on that individual's network of proximate social influences in the form of family, friends and community.

Folk knowledge is an apt summary term for the type of knowledge patients acquire when seeking health advice from friends and family: that is, knowledge transmitted between people who share a cultural outlook that may sometimes be unfamiliar to wider society; knowledge acquired through lived experience or through a culturally filtered interpretation of the lived experience of others, rather than scientifically evidenced knowledge. Folk knowledge can also encompass what is often called 'common sense': that is, knowledge based not on expertise or any kind of esoteric knowledge, but on beliefs or propositions that *seem*, to many people, to be based on sound judgement. It provides an explanation as to why folk knowledge, in the form of health information and advice from friends and family, should prove so influential to the patient in receipt of it, even when it lacks objective evidence to justify its perceived value to the patient. It also explains why this type of knowledge can prove so resistant to scientific challenge.

The function of folk knowledge in healthcare has been referred to at least once before in the health literature. A 2002 study looking at communities of practice in the NHS noted that the 'folk', 'naive' or 'common sense' knowledge and practice of patients and junior staff had a disproportionately large impact on everyday thinking and practice in hospitals when compared to expert 'evidence', even among the hospital scientists. The study concluded that such knowledge should be harnessed to help

drive service improvements (Bate et al, 2002). This present study takes a balanced view of the potential merits and demerits of folk and common sense knowledge: after all, what is known or what seems obvious is not necessarily proven to be true. However, it is clear that the effect of such powerful chains of transmissions of belief and knowledge should not be ignored when considering how different types of patients manage their healthcare knowledge.

Implications

3.1.1 The role of nurse specialists

These study findings have interesting implications for patient clinical pathways once a patient's CHD condition has been stabilised. Firstly, it seems that, clinical expertise is vital at key stages in chronic disease management: for detailed check-ups and at times of acute illness or sudden health deterioration. Clinical expertise is not central to knowledge-seeking among established CHD patients enjoying periods of stable health, whose immediate needs lie in managing everyday life to their satisfaction. This suggests that practical knowledge and social support are generally more important than clinical expertise in areas such as long-term health maintenance, which many GPs also concede is something they are often ill-equipped to help the patient manage effectively.

Nurse specialists and cardiac instructors could play an enhanced role in patient CHD management and long-term health maintenance in new types of long-term care pathways discussed in more detail later in this section.

3.1.2 The power of friends and family to improve self-care

The patient interviews attested to the significant influence that friends and family can exercise over patient knowledge-seeking and decision-making, due to their cultural proximity and intimacy with the patient. Any strategy for long-term health maintenance needs to take account of these influential sources of patient knowledge, often invisible to the healthcare professional. It is already known that social context, socioeconomic status and social relationships can influence individual health, both directly and indirectly (Holt-Lunstad et al, 2010; Alter et al, 2006). This means that friends, family and associated community groups may well be better placed to influence a patient's health behaviours – for better and for worse – than any medic.

In addition, the social media that resulted from Web 2.0 have created spaces where comment is only lightly moderated; they have changed the rules of engagement. Such media are built on multidirectional relationships rather than hierarchies of authority, and a sense of community, however geographically dispersed and virtual. Jebb's 2010 Weightwatchers study appears to reinforce the perception that peer support is valuable in health maintenance; social media and new peer-to-peer marketing methods could be one means of utilising the trust patients have expressed in the knowledge they receive from 'people like me'. This is an area that merits further

attention: research is required to examine how the power of social networks and the selective influence of those closest to the patient might best be harnessed to encourage and motivate behavioural change for those patients who respond well to such an approach.

3.2 Result 2

In the following section, 3 results are grouped together for discussion purposes:

The quality of the GP-patient relationship affected patient knowledge-seeking behaviour. Patients who lacked a long-term positive therapeutic relationship with their GP were more likely to seek knowledge from other sources.

Poor communication with healthcare professionals in general also influenced patient knowledge-seeking behaviour. Nurse specialists and cardiac trainers were singled out as good communicators, and patients described feeling comfortable seeking knowledge and advice from them.

Despite evidence of patient engagement, there was little sense of patients' 'entitlement' to be more closely involved in their own healthcare.

Discussion

Three study findings are discussed here, as their implications relate closely to each other.

Trust Relations

It is known that the quality of a patient's relationship with a doctor affects behavioural matters, such as drug compliance and medical outcomes (Coulter et al, 2008; Haynes et al, 2002; Stewart et al, 1999). It is also known that GP behaviours are often used by patients as a proxy measure for quality of care (Bendapudi et al, 2006). The new finding that came to light in this study was the apparent inverse correlation between the quality of the GP-patient relationship and the degree of patient interest in seeking knowledge elsewhere. Patient knowledge-seeking practice seemed to be strongly associated with patient trust in his or her GP.

Any knowledge management intervention will need to address directly the issue of trust. We know trust in healthcare matters clinically: Calnan and Rowe (2002) show how trust appears to mediate therapeutic processes and exercises an indirect influence on health outcomes through its impact on patient satisfaction, adherence to treatment and continuity of care with a provider. Trust is known to be important specifically in chronic disease management, where there is likely to be a prolonged relationship between patient and health professionals (Moseley-Williams et al, 2002). However, trust relationships between healthcare staff and patients have been eroded by a number of factors: by multiple changes in the organisation and funding of the health service; by a loss of public trust in the caring professions brought about by medical scandals, such as the 1998 expose of medical attitudes behind the deaths of 29 babies at the Bristol Royal Infirmary and the more recent revelations of poor standards of care at the Mid-Staffordshire NHS Trust; by the rise in avoidable ward

infections; by a loss of public confidence in the reliability of scientific medicine, as witnessed in the ongoing public uncertainty about the MMR vaccine even though links with autism have been effectively disproven, and the concomitant interest in 'alternative' therapies even where there is little or no evidence of therapeutic efficacy; and by broader societal loss of confidence in public institutions and public figures. On the health provider side, there are also trust concerns, often expressed as practical and organisational concerns among the medical profession about the value and ethics of sharing medical knowledge with patients.

Patients in this study described four factors that affected their levels of trust in their GP's treatment decisions: the lack of time available to the GP to explain treatment decisions to the patient; the lack of time available to the GP potentially leading to rushed treatment decisions; GP-patient disagreements over the value of diagnostic checks; and the lack of a long-term personal therapeutic relationship between GP and patient.

The quality of the GP-patient relationship is likely to be only one of many factors affecting a patient's knowledge-seeking behaviour – after all, some patients may simply be more curious than others for a range of reasons that lie outside this study's scope. However, the findings showed a strong association between time-poor GP consultations, where the patient felt there was no time available to discuss concerns and a lack of a long-term therapeutic GP-patient relationship on the one hand, and patient interest in seeking knowledge regarding their condition from sources outside

of the GP surgery on the other. Conversely, it was noticeable that patients with a *good* GP relationship, where the patient was encouraged to discuss concerns during a consultation, and where there was an established relationship with the GP over time, were less likely to express an interest in seeking information elsewhere.

Patient knowledge-seeking took different forms, including patient requests for secondary referrals to a hospital consultant, a patient decision to move into private medical care, patient interest in searching for relevant online information, and the patient's consultation of close friends and family for alternative advice and information. To a lesser extent, it also took the form of patient interest in written literature on the relevant health topic, although this was generally considered by study patients to be raw material to assist discussion elsewhere.

It seems that trust and its knock-on effect on patient knowledge-seeking may well have important population health and health resource implications. On the subject of loss of GP trust leading to secondary referrals, it was noticeable that three of the more articulate men from higher socio-economic groups in the study had insisted on secondary referrals against the advice of their GPs. These kind of poor trust relations in primary care may help explain the 'inverse care law', whereby wealthier, more articulate patients, who are generally healthier than other social groups, but also more socially confident and articulate, actually manage to receive more care than other social groups. In English PCTs, the referral rate in 2006 for cardiology investigations for the poorest fifth of the population was 10.8 per 1,000 people, compared to 9.1 for the

richest fifth, even though rates of cardiovascular and ischaemic heart disease were twice as high in deprived areas as in wealthy ones (Cole, 2006).

Communication

Many patients in this study mentioned without prompting that they had encountered communication problems with hospital doctors, GPs, hospital nurses, district nurses and care workers that had either prevented them from gaining information that they were seeking at the time, or had in some cases impeded the medical treatment they were receiving. It is interesting to note how poor communication issues tie in with what is reported by patients more broadly in the quarterly Ipsos Mori Patient GP survey 2009/10 conducted for the Department of Health (figure 9.1).

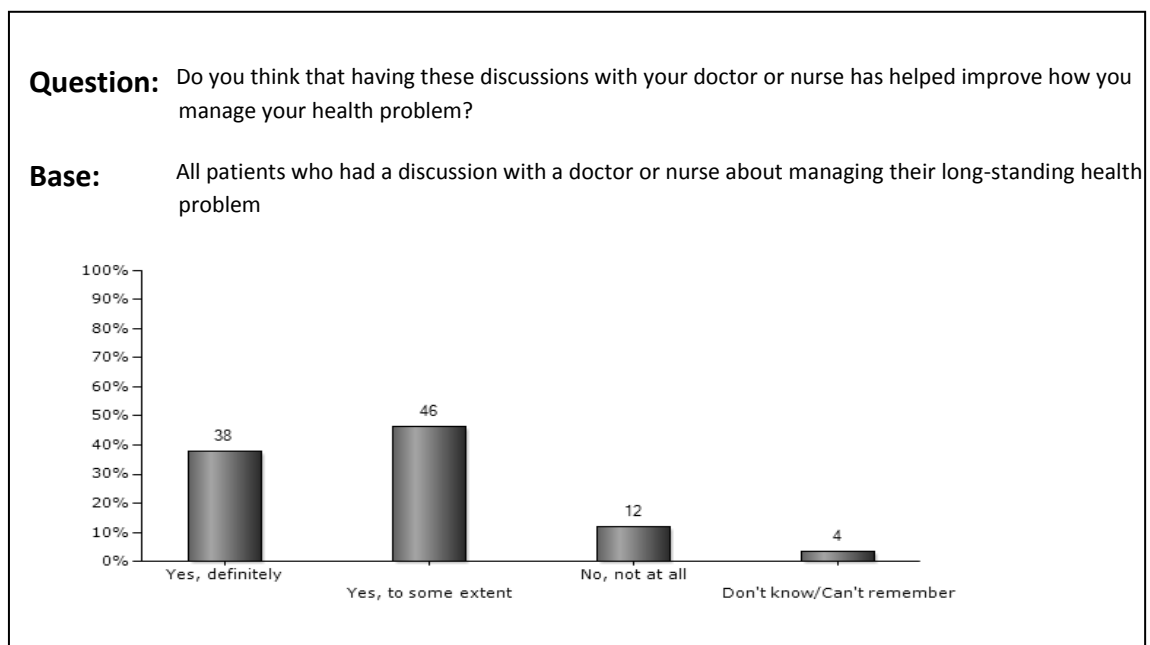


Figure 9.1 Ipsos Mori GP Patient Survey June 2009 for Camden PCT

Only 38% of the surveyed patients with long-term conditions in Camden PCT who responded gave an unequivocal yes to the question of whether discussions with a doctor or surgery nurse had helped to improve how they managed their health problems; 46% answered more equivocally and 12% stated that they felt such discussions to have been not at all helpful.

The survey does not reveal *why* such discussions proved so unhelpful, but one might reasonably surmise that such discussions were judged by the patient to be either uninformative or ineffective in, or irrelevant to, the task of improving their health problems.

By contrast, those study patients who had encountered nurse specialists and cardiac trainers were quick to praise them for their accessibility, good communication skills and the time they had available to spend with the patient: they seemed to demonstrate the kind of service provision and quality of communication that CHD patients in non-acute phases of illness valued most.

Implications

3.2.1 A new type of non-acute CHD treatment pathway

Poor communication between healthcare professionals and patients is not a new topic, but it appears to persist as an issue that both impedes patient knowledge-seeking in the surgery and re-directs it elsewhere.

Study patients made clear that knowledge derived through personal interaction played a key role in engendering trust in medical treatment. Healthcare think tanks such as the Kings Fund and the Picker Institute argue that training is needed to improve GP communication skills and to encourage GPs to promote chronic disease patient self-care, as the prevailing healthcare culture appears to militate against it (Coulter et al, 2006; Corben et al, 2005). It may, however, it may be more productive and tactically apt to 'disrupt' chronic disease management, rather than try to reform it. Instead of attempting to find ways of squeezing more time and continuity of care per patient from GPs, it might be more effective to find others in the healthcare system who can provide the service that patients seek and value.

The findings suggest that new types of therapeutic relationship are needed in the NHS model of chronic disease care. This further strengthens the case for extending the role of the nurse specialists in the long-term management of CHD: they could forge new types of therapeutic relationship that develop an enhanced role for the patient as co-manager of his or her health. Many primary care teams have already acknowledged the work of nurse specialists in making an impact on patient diabetes self-care, working in more practical and personalised ways that take into account the important role played by patient lifestyle and environment in managing diabetes. There are strong arguments for enhancing the scope of such roles in other areas of long-term chronic disease management, including CHD.

Some studies show that groups such as Weight Watchers help with weight loss management better than GPs, albeit in studies that look only at the short term. Alongside nurse specialists, regulated external agencies, using well-evidenced methods, *may* be better placed than primary care physicians and healthcare staff to take on the challenges, and develop the distinct skills and expertise required to manage the motivational aspects of long-term health maintenance. Nurse specialists could monitor patient care, and pioneer the use of telecare and greater patient self-management. GPs could then continue to focus on diagnostics, acute care and care of those whose very poor health requires close medical attention and more frequent medical intervention. The health advisory body, the National Institute for Health and Clinical Excellence (NICE) already recommends in its guidelines that GPs should consider referring overweight patients to a commercial provider, so there is already some policy movement in this direction.

Taking health maintenance out of the GP surgery and onto the high street may make sense – so much so, that many large high street chains already offer weight reduction plans and online advice and support. The problem is that the lack of a meaningful evidence base renders it impossible to judge what works for different types of patient in the long term. More research is required to establish exactly which aspects of dedicated weight loss programmes prove more effective than the GP surgery-based weight reduction efforts and why this is the case. In addition, more progress is needed in the area of motivational research: otherwise, it is likely that surgical solutions to the

problem of poor health behaviours will increase their dominance and popularity among patients.

Further research is required to examine the impact on patient quality of life and health outcomes of enhancing the role of nurse specialists, cardiac trainers and/or dedicated private sector partners in CHD management and patient long-term health maintenance.

3.3 Result 3:

The Internet Paradox: a popular source of patient medical knowledge was simultaneously regarded as untrustworthy.

Discussion

This finding is only new in that it brings together findings made on discrete aspects of it previously by different study authors - that the internet is a popular knowledge source for patients (Nicholas et al, 2003), yet the information it provides is often regarded as untrustworthy (Damman et al, 2009; TNS Survey, 2007). This suggests that patient curiosity should not be mistaken for patient trust in the context of seeking health knowledge and information on the web.

Lay literature vs. the medical mainstream

This finding also suggests that patients may be currently unsupported by advice from

their GP practice when it comes to web browsing and are largely unaware of NHS-recommended sites (Greenberg et al, 2004). As discussed in the literature review section, an analysis of online content concerning hypertension (an important aspect of CHD management) revealed that alternative remedies dominated the lay literature about hypertension, but were not addressed in the major medical websites aimed at patients (Dunn et al, 2001). This may be a more general problem with the mainstream medical literature, both on- and offline, which tends to ignore unevaluated or disproven remedies advanced elsewhere.

Despite a generational lack of familiarity with online information-seeking among many of the patients, there was a definite interest among most of the internet-users in reading online information that went beyond that available to them on official, medically endorsed websites. This suggests that mainstream medicine simply cannot afford to ignore popular interest in sources that provide alternative health advice and associated types of healthcare information of the kind that generally goes unevaluated and exists under the radar of mainstream medicine.

Attitudes to the internet and web-based information may be era-specific, in that subsequent generations of CHD patients will have a more developed sense of the web and online information that comes with technological familiarity, but it is hard to predict whether there will be more or less trust in the internet as familiarity replaces novelty. Knowledge-seeking outside of the GP practice is likely to take on more importance as long-standing patient relationships with a single GP become increasingly

rare, and GP consultation time per patient is unlikely to increase. This means that patients are likely to be even more exposed to unmediated health advice and information.

In the near future, pay walls may start to create a two-tier internet knowledge base; however, web-based information is likely to remain an important source of patient knowledge and needs to be fully utilised by the medical mainstream.

Implications

3.3.1 Scientific evaluations of alternative therapies aimed at lay people

It seems that NHS-approved websites need to take a more comprehensive view of the kind of information available to patients elsewhere on the internet: at present, it seems that much mainstream health information on the web effectively ignores the range of views and 'alternative' medical opinion available to an internet user. It might be a valuable service to patients to demonstrate how to critically evaluate information available to them. It might also be valuable to publish scientifically evaluated appraisals of alternative remedies on mainstream medical websites, expressed in layperson's language.

In response to the problem of trust in online patient information, the Department of Health established an 'Information Standard' mark in November 2009: the symbol indicates that the organisation publishing the online information concerned has been

certified as providing evidence-based health and social care information. It remains to be seen whether the public will learn to recognise the symbol, and whether organisations will come to regard certification as necessary. Such advice, however, may not prove decisive in online knowledge-seeking for all patients: some may yet prefer to look for web-based information from 'people like us', irrespective of its scientific validity (Sillence et al, 2007a).

3.4 Result 4:

Secondary knowledge-seeking: patients tended to regard written information as less relevant to them, as it could not address the specificities of their condition. However, press alerts that contained healthcare warnings requiring a fast response had been demonstrably influential sources of patient knowledge.

Discussion

This result adds to the existing evidence that written information lacks the personalisation that CHD patients prefer (Marie et al 2006; Richard et al, 2005). It is also known that the popular press is good at communicating urgent health information, even if it tends to scare as well as inform its readers (Nisbet et al, 2002).

Implications

3.4.1 Written literature and online applications

Written CHD literature aimed at patients could have a dual use: firstly, to communicate with those patients who have no direct access to the internet; and secondly, to direct

all other patients to interactive sources that could be customised to meet patients' individual requirements. Literature and leaflets could be linked to applications such as interactive online websites, phone apps and interactive health communication applications (IHCAs). The existing literature reports that IHCAs can have a statistically significant positive effect on patient knowledge, social support and clinical outcomes: further research and trialling of IHCAs is required to measure their effect on chronic disease management.

3.5 Result 5:

Despite considerable engagement with their healthcare, NHS-held patient data was of limited interest to patients.

Discussion

The existing literature already warns that the availability of personal electronic health information to patients risks a lack of take-up unless such records are closely aligned to patient attitudes, self management practices and information needs (Greenhalgh et al, 2008, 2010; Ralston et al, 2007). This was confirmed in the study: patients showed little interest in accessing their health records, with the exception of a few who had concerns about the accuracy of past input.

The NHS, for reasons of organisational transparency, is likely to make patient files accessible to patients online once the necessary online security has been identified. A study of IBD patients identified four aspects of communication technology that

patients described as finding useful, namely, when the technology promoted a sense of illness ownership, when it promoted patient-driven communication, personalised support, and a sense of mutual trust (Winkelman et al, 2005). Such findings are likely to have a wider applicability to chronic disease patients in general.

Potential patient indifference to online health records should not be mistaken for indifference to online content per se. Computer and palm-top applications are hugely popular contemporary communication methods; simple applications such the patient appointment reminder text service have been introduced by a number of hospital outpatient departments and GP surgeries to positive patient acclaim (BMA, 2009). If online patient-related data is made available online that makes the management of any aspect of healthcare easier for the patient, it will be utilised. The skill lies in identifying the very different knowledge and information needs of CHD patient, as witnessed in this current study.

Implications

There are broader implications for developments in online healthcare.

3.5.1 Electronic health records and interactive patient access

In terms of knowledge management, the introduction of electronic health records appear vital to a more flexible healthcare system, where patient information can be compiled and shared more easily across disciplines and locations. There are currently plans to introduce patient summary care records, a scaled down version of health

records, containing only the most basic patient information: as such, it is to be welcomed.

If patients are encouraged to take a more active role in their own self-care, it seems logical that it would be useful for online care records to have an associated interactive patient access area, where patients could record health details that need to be monitored over time. Such a space could also be used to give patients access to interactive health communication applications (IHCAs) to assist with health maintenance.

Further research is required to examine the technical feasibility and clinical effectiveness of such online developments.

3.5.2 Patient self-care and telecare

Telecare is another aspect of patient-facing technology that generates little enthusiasm at a stage when it is still overcoming teething troubles and is yet to make any real-life breakthroughs in NHS healthcare. At present, there is no practical means of consistently capturing and monitoring much of what patients could do, or already do for themselves. So, for example, of those study patients who did take their own BP readings, only three reported these back to their GP surgery in any form; only one had been trained by their GP nurse to ensure they were taking the readings properly. Blood pressure readings are a simple example of an easily acquired skill that, once taught, would free the patient from the time taken to attend the GP surgery for this

purpose, and help produce regular blood pressure readings under more typical conditions. Exceptionally, GPs at the Houghton Surgery in Yorkshire have already successfully enabled such online patient self-reporting. The existing literature suggests that patient BP self-monitoring should be encouraged: recent hypertension studies show that patient self-monitoring and reporting can significantly reduce hypertension in randomly selected patients (McManus et al, 2010; Agarwal et al, 2011).

Despite the reported current low-level indifference to the introduction of telecare in primary care practice, such developments could carry practical benefits both for patients and healthcare providers: in the US, a 2010 study by the PWC Health Research Institute reported that the Veterans Health Administration had reduced patient use of their 'real-life' health facilities by 30 percent over six years by introducing telecare, in the form of remote consultations, diagnosis and sometimes even treatment, using video or online links.

Advances in telecare and home care diagnostics could be used in the NHS to increase patient autonomy, as well as reduce healthcare costs. This ties in neatly with the idea of creating a new role for CHD nurse specialists: telecare would increase the volume of patients each nurse specialist could manage, allowing them to intervene more strategically with patients and to develop expertise in remote diagnosis and self-reported health data.

3.5.3 The patient contribution to clinical knowledge

Websites and the patient-centred online applications pioneered by *patientslikeme* and *LAMsight*, discussed in detail in chapter 7, demonstrate the potential value of aggregating patient self-reported data for the purposes of medical research and drugs evaluations, as well as the potential appetite patients may have for contributing directly to new forms of medical research.

This kind of self-reporting opens up the possibility of new research methods, especially as generations of patients become more computer-literate and willing to share personal information online. So for example, there is much that is not yet known about the effects of combining drugs that are prescribed for different diseases, which patients are ideally placed to comment upon directly. In this study's small patient sample, there was considerable experience of co-morbidity and the associated polypharmacy: 28 out of 34 patients had more than one chronic condition and nearly half were taking four or more different medications every day, with 5 taking 10 different medications or more daily. Some mentioned health effects that they attributed to unanticipated drug interactions; some had found methods of minimising side effects by altering the time of the day they were taken. Aggregating such data might deliver fast preliminary indicative results and useful hypotheses that could be taken up by more formal medical research.

3.6 Result 6:

Patients reported using a range of 'alternative' medical remedies and seeking medical

advice from 'alternative' therapists. Such remedies were generally used to supplement, rather than replace orthodox medicine: its use by patients in this way appeared to be unaffected by any evidence presented regarding its lack of efficacy.

Discussion

On the basis of the patient interviews, it seems unlikely that medical evidence alone would deter many of them from trying unproven or disproven medical remedies, which are often used to address symptoms that mainstream medicine fails to resolve, such as pain management, nausea or other non-life threatening but debilitating patient symptoms. Patients reported that, with a few exceptions, they felt there was little opportunity to discuss alternative medical remedies with GPs, thus often depriving patients of informed medical opinion.

Patient users of 'alternative' therapists also praised the time and attention they devoted to the patient, which research showed to make a significant impact on patient trust. Many patients seek out and enjoy therapeutic relationships with alternative therapists as what they view as an important part of their healthcare process.

Implications

3.6.1 Mainstream medicine and alternative therapies

In recognition of the scale of the alternative therapies industry, it seems logical that orthodox medical authorities, especially GPs and clinic nurses, ensure that they are

providing evidence and opinion on the efficacy of these treatments, even if patients choose to ignore it.

3.6.2 Mainstream medicine and its caring role

The kind of time-taking and care described by patients when visiting 'alternative' medical therapists reflects poorly on current NHS service provision, denuded of what some patient interviewees described as an important aspect of their alternative therapy often missing from the medical mainstream.

3.7 Result 7:

One size does not fit all. Patient responses to Cardiac Rehabilitation Programmes showed that, whilst some patients, notably but not exclusively women, actively enjoyed and appreciated the CRPs they had attended, some of the younger CHD patients in employment and some of the older, more educated men had felt out of place. In addition, the health maintenance support provided was felt by many patients to end too soon.

Discussion

Whilst the existing literature testifies to the efficacy of CRPs, their effectiveness is marred by the fact that, among those who are offered its services, many do not stay the course (BHF, 2010b; Pell et al, 1996). The patient cohort responses, coupled with the existing literature, suggest that there are three main factors that influence the effectiveness of such programmes.

One factor is that such courses require a degree of personalisation and choice for patients if they are to be effective in terms of patient uptake and adherence. The second factor concerns the duration of the programme: many patients felt they would have continued to benefit from the kind of health maintenance support they had received in their CRP had it been continued in some form after the 6-12 week course had come to an end. The third factor is ease of access to a CRP, in terms of travel, cost and time of day that such a course is available.

This finding is partially supported by the existing literature, which reports that, despite considerable promotion of the Expert Patient Programme in particular, no one patient-oriented knowledge management intervention is known to satisfy a heterogeneous patient population (Newbould et al, 2006). There were indications among the patient group interviewed that, for example, group aspects of learning were appreciated by some and actively disliked by others; younger working-age CHD patients felt uncomfortable among older retired patients; some CHD patients felt too ill to attend or alternatively were too busy to attend during the hours offered.

Implications

3.7.1 A more tailored approach to CRPs

This finding suggests that if cardiac rehabilitation programmes are to be effective for all patient types, the programme will need to be made available to patients in different formats. So for example, an online interactive learning programme, coupled with short video presentations could be more attractive to younger, technologically literate,

time-poor patients. Cardiac nurse specialists could be available online to answer questions; additional exercise classes could be organised to run outside working hours or at weekends; greater efforts could be made to place patients with longer term exercise providers at reduced costs.

More research is required to investigate the range of options that might appeal to different types of CHD patient and measure any potential increase in uptake and health outcome that may result.

4. DISCUSSION OF RESULTS RELATING TO THE SECOND RESEARCH QUESTION

4.1 Result 1:

A development of knowledge management theory as it applies to the relationship between patient knowledge and organisational knowledge creation. Patient-generated knowledge derives from the partial, subjective and often tacit nature of patient experience and understanding. It may require knowledge conversion by a third party to give it organisational relevance.

Discussion

In some ways, this finding seems self-evident: patient-generated knowledge is experienced first at a personal, subjective level. Some patient knowledge is tacit, rooted in patient experience and practice: as such, it is not necessarily regarded as

knowledge by the patient, but more as an activity, or a 'way of doing'. This observation is consistent with the theory of tacit and explicit knowledge in the existing literature: furthermore, it applies and develops Nonaka and Takeuchi's theory of organisational knowledge creation in relation to patient knowledge generation and patient knowledge conversion. It does so by explaining the knowledge trajectory from tacit and explicit forms of patient knowledge to organisational knowledge creation observed in this study.

This result is based on applying existing theory to new areas of organisational activity: its purpose is to try and explain at an abstract level how patient knowledge can be rendered so as to be of organisational benefit. This extension of organisational knowledge theory to patients also helps to explain why patient knowledge may not be recognised as potentially valuable organisational knowledge in its unconverted form. Such value is unlikely to be apparent unless the knowledge is processed through a third party, a person who can engage creatively with patient knowledge and its organisational implications. It shows the ongoing relevance of Nonaka and Takeuchi's knowledge conversion theory and its generalisability to patient knowledge and healthcare systems.

Patient knowledge may not always be recognised as such because it may sometimes require an intermediate stage, involving a third party observer, to isolate and identify the features of that knowledge that can be applied more broadly. This is the step required to give patient knowledge organisational relevance or value. In this study,

the results that follow were arrived at using this conceptual method and set out in diagrammatic form in chapter 7 (figures 7.1, 7.4 and 7.6).

Implications

4.1.1 Organisational learning from patients

The kind of organisational knowledge gleaned from knowledge embodied by patients cannot be gathered using the kind of tick-box questionnaires and patient surveys that often characterise patient consultation: such methods are useful if the organisation needs to arrive at quantitative 'yes/no' answers to relatively straightforward questions. Even focus groups have the disadvantage of taking patients out of their situation. Patient interviews are often best conducted where the patient is in context and is able to both talk about and *show* what they mean. The interviewer may need to engage with each patient and their activity: after a number of interviews, common features may become apparent which can lead to organisational learning that has greater depth and texture.

4.2 Result 2:

The development by patients of personalised health records revealed their tacit knowledge of the informal workings of the NHS system for managing patients. It also revealed their more explicit understanding of the need to have their own medical record system as a record of, and a guide to, their dealings with health providers.

Discussion

Patient home-based health records

No discussion of the existence of any form of patient-generated health record has been encountered in the existing literature. It was only in the course of a series of home visits to patients for interview purposes in this study that the author noticed their existence. While the character of patients' notes, memos, document collections and diary entries does vary considerably, especially in terms of the detail recorded, it is no exaggeration to describe what many of the study patients had developed as constituting a home-based health record. This took many forms, both simple and more complex, and could contain the following range of information: a list and accompanying details relating to a patient's prescription drugs; details of any other medication or therapies prescribed by 'alternative' therapists; folders of healthcare correspondence; test results; a record of past and future healthcare appointment dates and any outcomes of appointments attended; health-related observations over time, such as units of alcohol drunk, weight or BP measurements; and records of names and contract details of key healthcare personnel. This was both a record of patient healthcare to date and of their acquired learning about the system within which they try to co-manage their healthcare. The records included key details about past treatment and a guide to try and ensure continuation of treatment into the future.

Limitations

It would have been useful to request unrestricted access to patients' home-made

records, so that they could have been examined in greater detail in a return visit to patients' homes. In this way, the types of knowledge evidenced by the patients in their records could have been properly categorised: this, in turn, would have enabled an examination of the impact of that knowledge upon their decision-making and consequent health-related behaviours subsequently. This kind of close evaluation remains to be done and could be part of a further study.

Patient pathways

The existence of such home-made records, together with patient accounts of the administrative and communication problems encountered that had had negative consequences for the quality of their healthcare, suggests that the current approach to non-acute chronic disease management is often overly bureaucratic, poorly co-ordinated and difficult for the patient to participate in and plan.

At present, GPs are responsible for co-ordinating a patient's primary and secondary care: but GPs are not in a position to improve upon the fragmented and various systems used by different clinics and specialties in secondary care. In fact, no one person administers the CHD patient pathways that straddle primary and secondary care, often in the form of hospital outpatient clinics. When a patient has multiple chronic diseases, the complexity of their healthcare escalates: patients were eloquent in describing the challenges of participating in the healthcare system under such circumstances; some of their comments are captured in chapter 6. As noted in the literature, the organisation of healthcare professionals into distinct clinical specialties is an organisational form suited to acute care and the treatment of infectious diseases

– it does not work well for the effective management of chronic diseases (Holman et al, 2000).

Implications

4.2.1 A multi-disciplinary team approach

There is a strong case for reviewing how a long-term chronic disease pathway such as CHD is managed and who should manage it. Effective co-ordination of a CHD patient pathway requires there to be one person responsible for a patient's healthcare across all health platforms, be it primary or secondary care, clinic-based or home-based care, especially once home-based chronic disease management becomes more prevalent through the introduction of telecare. One option is to give the nurse specialist, who, in her or his new role, would be in regular contact in some form with stable CHD patients, the responsibility for overseeing the CHD patient's care pathway, as part of a broader chronic disease multi-disciplinary team approach. An effective chronic disease pathway would dispense with clinical specialties, in favour of multi-disciplinary teams organised around the multi-morbidities characteristic of older CHD patients.

A more flexible, more patient-centred administrative system would also manage the patient pathway more efficiently, irrespective of its basis in primary or secondary care. This kind of organisational measures may become more thinkable as outpatient care is increasingly moved out of hospitals and into localised treatment centres and practice-based clinics.

Further research is required to examine the case for a more streamlined and co-ordinated approach to the management of CHD across primary and secondary care, taking into account the associated financial costs and clinical outcomes. Such an approach would need to win the hearts and minds of senior consultants, whose support would be central to any move towards managing knowledge in less clinically demarcated ways (Ferlie et al, 2003; Bate et al, 2006).

4.2.2 Patient access to knowledge and information

Patients are becoming more computer literate: soon, most will have access to a computer or handheld terminal that can be used to receive and transmit information easily and cheaply. For this to transform NHS healthcare, as well as potentially reduce costs, it will be vital to know what kind of information and knowledge patients want or need to help them manage more of their own healthcare. Patient's homemade health records suggest that patient healthcare will be highly variegated, with different patients requiring different levels of knowledge and information to assist them, so any system seeking to increase patient self-care will need to take this into account.

4.3 Result 3:

Many patients described difficulties with their long-term health behaviours. Their degree of knowledge about how to manage health behaviours appeared to play little, if any, role in determining their actions. It would appear that patient knowledge lacks influence over patient behaviour when the outcome of that behaviour is deferred to an unknown point in the future.

Discussion

This result adds weight to findings in the existing literature which state that improving patient understanding of health-related issues is not a panacea and does not necessarily result in better health outcomes (Lorig et al, 2005; Coulter et al, 2007); that problems such as a tendency towards obesity can often be managed in the short term only to return to baseline in the longer term (Brownell et al, 1992).

In this study, a cohort of highly knowledgeable and mostly highly motivated cardiac patients reported their inability to adhere to what they knew to be a satisfactory health regime in the long-term. At the same time, a knowledge gap appears to have opened up between research evidence, including the findings of this study on the one hand, and clinical practice, including GP questionnaire respondents in this study, on the other. Belief in the effectiveness of patient education to improve health behaviours appears to persist among many of the GPs questioned in this study, despite the evidence to the contrary in much of the existing literature. Knowledge-deficit theory does not appear to explain poor health behaviours, nor does the knowledge deficit approach succeed in improving health behaviours in the longer term (White et al, 2010; Otto et al, 2010).

Chronic disease management is very different from acute medicine in terms of the linkages between cause and effect: most people will willingly take medication to cure an acute attack of pain or an infectious disease; few people would knowingly indulge in

an activity that had the immediate effect of giving them a life-threatening illness; indeed, the aftermath of an acute episode such as a heart attack is likely to shake many people out of the lethargy they may have felt about diet and exercise – in the short term.

The often intractable nature of poor health behaviours for many people is partially explained by a range of ‘upstream’ risk factors: environmental and socio-economic conditions such as method of travel to work, healthy eating costs and time poverty.

‘The local gym is disappointing – it used to have a Friday class for seniors, but now the new classes aren’t suitable.’ (Female, 58)

In addition, psychological factors such as self-esteem, learned stress responses and acquired eating habits make up some of the many factors that have been used to explain the ‘causes of the causes’ of poor health behaviours (Marmot et al, 1999). Long-term health behaviours are much harder to subject to self-regulation and, as recorded in the review of the literature, studies purporting to examine the outcomes on changing health behaviours are often conducted over too short a time span to report reliably on the effectiveness of a given intervention for long-term health maintenance.

The outcome of most health behaviours, good and bad, tends to accumulate over time, along with the associated chronic diseases. Negative outcomes associated with poor health behaviours, in the form of chronic disease symptoms, are rarely experienced in the short term. They therefore involve a degree of self-denial in the present in order to improve the odds against morbidity or premature death at an unknown date in the future.

Many of the patients interviewed described their experience of failing to manage their health behaviours to their own satisfaction, although none attributed their failure to 'upstream' causes of poor health: indeed, most attributed their failure to adhere to diet, alcohol, smoking or exercise advice to personal weakness. This made it difficult for them to view poor health behaviours as a matter requiring medical attention, as opposed to personal self-control.

GPs such as those who responded to the study questionnaire currently appear to have little to offer such patients, despite sharing the view that health maintenance is a significant problem for many CHD patients. GPs often identified the patients themselves as the problem, along with lack of GP time available to educate such patients. On reflection, patients appear to be responding rationally when they state that they do not think it appropriate that poor health behaviours should be addressed through the GP surgery: managing health behaviours effectively is rarely a traditional medical matter that can be solved with medication, re-education by the GP nutritionist or a monthly weigh-in with the GP nurse. All of these may have short-term effects, but

once the session of 6, 12 or 24 visits ceases, so too does their effect: in other words, health behaviours is itself a chronic problem which needs to be managed over a lifetime and in new ways.

Very little is currently known for certain about how to improve health behaviours over the longer term. In the meantime, the BMJ reports that the annual rate of operations for gastric banding and gastric bypasses rose tenfold in 2007 (Burns et al, 2010). As invasive surgical procedures, these are not without health risks, but they have proved successful at ensuring good weight management when compared to behavioural methods (Favretti et al, 2007). They work, not by improving health behaviours, but by re-engineering the body to make overeating almost impossible and thereby forcing a reduction in food intake, leading to weight loss. Their growing popularity is a measure of the failure of the behavioural sciences to enable successful long-term weight loss for many desperate patients.

Implications

4.3.1 The evidence base for patient interventions

On a clinical front, more research is required to improve the evidence base for the effectiveness of any new and existing interventions aimed at helping patients manage positive health behaviours and self-motivation in the long term.

4.3.2 New patient pathways for long-term health maintenance

On an organisational front, the findings suggest that that new long-term pathways might support CHD patient health maintenance more effectively, as discussed earlier. Support with diet, exercise and lifestyle issues may best be tackled over the long-term by organisations dedicated to such areas of work, either inside or outside the NHS.

5. CONCLUSION

The results of this study are grounded in the interviews and observations of the study patients and are rich in depth and textual analysis. The results have the status of theses in relation to the CHD patient population as a whole. The overall thesis that binds them together is that a better understanding of CHD patient knowledge in healthcare, both in terms of knowledge-seeking and knowledge generation could enhance the management of CHD. The study's implications for CHD management, both now and in the future, were set out in detail in the preceding discussion.

5.1 Summary

The discussion examined how our understanding of patient knowledge-seeking could help improve the effectiveness of some current knowledge management interventions aimed at CHD patients, most notably cardiac rehabilitation programmes. It identified interventions where further development could be encouraged, notably online patient applications designed to assist patient self-care such as IHCA's and interactive capabilities that could be associated with e-records. By implication, it also helped

identify the kind of interventions that might potentially be downgraded in importance, due to their relative ineffectiveness, notably patient education programmes aimed at improving long-term health behaviours.

The discussion also identified that the effective treatment of CHD and other chronic disease strongly suggest that changes to how its treatment is administered and organised are needed. Finally, it examined the finding's implications for long-term health maintenance, where nurse specialists might help ring the changes.

In the matter of knowledge-seeking, patients in the study placed their greatest trust in knowledge derived through personal interaction rather than the internet or written literature. Patients sought the knowledge and advice of three different social or professional groups: GPs and consultants; nurse specialists and on occasion cardiac trainers and family and close friends, as well as other patients. The study results showed that patients sought three very different types of knowledge about their condition from these groups: they sought expert clinical knowledge from GPs and clinicians, personalised, practical knowledge from nurse specialists and cardiac trainers, and 'folk' and common sense knowledge from friends, family and sometimes other patients.

Different types of knowledge-seeking tended to occur at different stages of the disease trajectory: expert clinical knowledge was most highly sought in crisis periods, where the patient's CHD became unstable or acute. More personalised practical knowledge

was needed during periods of disease stability. However, 'folk' and common sense knowledge was a feature of patient knowledge-seeking at any stage of their disease trajectory, although it was most strongly associated with periods of disease stability. At different times, a patient's friends, family or other patients acted as sources of knowledge that included, but also extended beyond, mainstream medical knowledge and opinion to encompass alternative medicine and other approaches to CHD management based on received wisdom and personal or third-hand experience. The value of such 'folk' or common sense knowledge was highly valued and often highly trusted by patients, due to the trust they placed in the motives of the individuals providing that knowledge. This sometimes meant that any negative scientific evaluation of such remedies carried less weight than might be imagined.

In terms of knowledge creation, the study indicated that patients do indeed generate knowledge in the course of managing their CHD. It also showed that such knowledge might sometimes require conversion through a third party in order to take the form of organisational knowledge that might be of benefit to an institution as a whole, or to a broader group within it. The author modelled the mediations required to convert patient knowledge, including tacit knowledge, into organisational knowledge, and also used that model to show how it had worked in the case of two patient-generated findings.

The first patient-generated finding resulted from the way in which patients made sense of their experience of negotiating the problems inherent in seeking non-acute treatment for their CHD. Many developed home-based patient health records of

varying degrees of detail and sophistication in response. These records were often a guide to action, in that they encapsulated much of the knowledge patients felt they needed to manage the administration of their CHD treatment in the event of breakdown in the official NHS administrative system. Some records also developed beyond this, and contained records the patient chose to keep to assist them in other areas of self-care.

The second patient-generated finding resulted from the manner in which patients individually made sense of their experience of long-term health maintenance. Many described how long-term health goals were often derailed by short-term health behaviours, irrespective of their knowledge of longer term consequences. In different ways, many patients described, at a subjective level, what the author was able to express more generally by making sense of the collective experience: that is, that long-term health behaviours cannot be wholly managed through a patient's conscious understanding of the consequences of that behaviour, when those consequences are deferred to an unknown point in the patient's future.

5.2 Future work

The study advances the case for developing its theses in a number of directions:

Further research is needed to assess the generalisability of the author's theory of patient knowledge conversion, as modelled and discussed in chapter 7.

Research is required to evaluate whether nurse specialists, with their more practical personalised approach to the care of medically stable CHD patients, coupled with treatment methods made possible through telecare technology, could help transform the CHD patient clinical pathway in terms of long-term health maintenance.

Further work is needed to examine whether tightly regulated private sector involvement in managing aspects of long-term health maintenance might be of financial benefit to the NHS and might prove more effective for patients.

Research is needed to examine whether the administration and organisation of CHD that currently straddles so many different specialties and tiers in the healthcare system would benefit from a new clinical model of chronic disease management, organised around the multi-morbidities so common in older patients.

Research is needed into how patient social networks and other forms of online communication may advance (or retard) patient engagement with mainstream scientific medicine.

Further research is needed into how new forms of web-based communication are developing new forms of patient-led scientific enquiry.

Above all, there is an urgent case for better and longer term evaluations of the behavioural methods currently used to help manage patient health behaviours, as an area of healthcare that is set to grow as chronic disease escalates.

Further work is also required to establish whether these findings find a resonance in different patient groups or in representative samples of the patient population as a whole. Alternatively, sensitively conducted pilot studies and small-scale experiments in real-life situations can be a more practical measure of effect.

However, such pilots are only truly useful when considerable methodological rigour is applied to analysing and evaluating them: all too often, this is an afterthought in healthcare research.

5.3 Context

In the coming decades, increasing rates and prevalence of chronic disease, including CHD, will create new strains on healthcare systems, not just in the UK, but globally. Chronic diseases are now the main cause of death and disability worldwide, representing 60% of all deaths, and have overtaken infectious disease as the main causes of death in the rapidly growing urban centres in of the developing world (WHO, 2011). There is considerable policy consensus that increased patient responsibility and patient self-care will be necessary: a clearer understanding of how patients seek to understand and to manage their condition is needed to help shape the kind of services that increased patient clinical involvement will require.

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APPENDICES

Appendix A

Anonymised list of CHD patients interviewed May – August 2009

Patient ID	Gender	Age	Marital Status	Education Quals.	Ethnicity	Years since diagnosis	Add. chronic conds	Daily Medication
20	M	75	Married	Degree	White British/Irish	4	1	1
21	M	78	Married	Degree	Chinese	1	4	12
22	M	81	Married	None	Afro-Caribbean	10	3	6
23	M	77	Married	Vocational quals	White British	12	1	3
24	M	88	Partner	Vocational quals	White British	1.5	2	4
25	F	68	Married	Degree	Australian	17	1	9
26	M	53	Married	A levels	White British	5	1	13
27	M	86	Widowed	Degree	Swiss	3	1	5
28	M	75	Married	School matric.	Indian Asian	13	0	4
29	M	70	Married	Degree	White S African	18	2	6
30	M	55	Divorced	Vocational quals	Greek Cypriot	3	0	7
31	M	58	Married	Degree	Canadian	<1	0	5
32	M	84	Married	Degree	White British	19	0	3
33	M	57	Single	Degree	White British	10	0	3
34	F	75	Divorced	None	White British	19	3	8
35	M	79	Widowed	Degree	White British	18	2	6
36	M	54	Married	Degree	Egyptian	7	4	8
37	M	73	Married	Degree	White British	25	2	11
38	F	58	Married	Degree	White S African	2	1	10
39	M	81	Widowed	None	White British	34	3	11
40	M	60	Married	Degree	White British	9	1	3

Patient ID	Gender	Age	Marital Status	Educational Quals	Self-identified ethnicity	Years since diagnosis	Add. Chronic diseases	Daily medication
41	M	77	Married	School matric.	White British	12	4	10
42	F	66	Married	School matric.	White British	9	2	2
43	M	62	Widowed	None	Sri Lankan Asian	20	4	4
44	F	84	Widowed	School matric.	Irish	36	2	1
45	F	77	Widowed	None	White English	17	1	3
46	M	56	Divorced	Degree	White English	7	1	3
47	M	57	Married	None	Bangladeshi Asian	7	2	8
48	F	90	Widowed	School matric	Irish	20	2	8
49	M	68	Partner	School matric.	New Zealand	4	1	9
50	M	77	Married	Degree	White British	7	1	3
51	M	81	Married	None	White British	10	1	6
52	M	56	Divorced	Degree	Indian Asian	10	1	4
53	F	63	Widowed	None	White British	15	1	8
54	M	57	Married	Degree	White British/Irish	9	0	2

APPENDIX B: PATIENT LETTER OF INVITATION

Camden Study
Camden Primary Care Trust
Room 235
79 Camden Road
London NW1 9ES

email: camdenstudy@btinternet.com

Dear

Invitation to take part in patient research

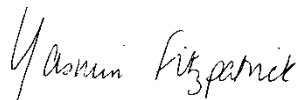
I am conducting research into how patients manage their long-term illness or condition and I would like to invite you to take part.

The research will involve talking to me at a time that suits you. I will ask you questions about your long-term condition and your medical treatment. It will not involve any kind of physical examination, nor will it affect your medical treatment. The discussion will be confidential and will not be passed on to anyone else, including your doctor.

I have included an information sheet and a reply letter. The information sheet should cover most of the questions you have. Please let me know if you can take part by signing the reply letter and posting it to the address above. Alternatively, you can send me an email to the email address printed at the top of this letter.

If you do take part, I will contact you to arrange a meeting at your convenience, where there will also be an opportunity to ask me any further questions. I would be delighted if you decide to participate, but I also understand that you may have reasons that prevent you from doing so.

Best wishes,

A handwritten signature in black ink that reads "Yasmin Fitzpatrick". The signature is written in a cursive style with a large initial 'Y'.

Yasmin Fitzpatrick

PhD Researcher

Camden Primary Care Trust

APPENDIX C: PATIENT REPLY FORM



**Please use reply paid envelope or send to the address at bottom of page.
Thank you.**

Study: How patients manage long-term health conditions

Yes, I think I would like to take part in this research. I do not need to decide until I have asked any other questions I may have. I also understand that I am free to withdraw from the study at any time.

Your Name:

Contact details

(Only fill in numbers you are happy to be contacted on)

home phone:

mobile:

work:

email address:

It is best to contact me at the following time of day:

Signed

Date

Please return in freepost envelope provided or to:

Yasmin Fitzpatrick, Camden PCT, Room 235, 79 Camden Road, London NW1 9ES.

Or you can send an email to camdenstudy@btinternet.com. Thank you.

APPENDIX D: PATIENT INFORMATION SHEET



INFORMATION SHEET

Research study: how patients manage long-term health conditions

You are being invited to take part in a research study. Before you decide, you may wish to know why the research is being done and what it will involve. If you return the reply letter, you can arrange to ask me about anything that is not clear or you can contact me by email on camdenstudy@btopenworld.com.

1. What is the purpose of the study?

This study is looking at how patients find out about, understand and manage their long-term illness or condition. The aim is to examine how health services could improve the involvement of patients in managing their long-term condition. The study will form an important part of a PhD academic paper that will be written in 2010.

2. Why have I been invited?

I am asking patients who are 35 and over and have a long-term condition involving their heart or circulation to take part in this study.

3. Do I have to take part?

It is up to you to decide whether or not to take part. I can discuss with you the research and any questions you may still have; you can also keep this information

sheet. If you decide to take part, you will be asked to sign a consent form; even then, you will be free to withdraw at any time and without giving a reason. This will not affect the care you receive from your doctor.

4. What will happen to me if I take part?

We will meet for about 45 minutes at a time and place that is convenient for you. I will ask you some questions about how you found out about your medical condition and how you currently manage it. The interview may be recorded on audiotape and I will take notes.

I may ask if I can observe one of your visits to your doctor so that I can see how the doctor discusses your health with you.

If your doctor has asked you to do anything by yourself to manage your condition, such as take your own blood pressure or take any other kinds of measurement, I would also like to observe how you do these tasks, so that I can better understand how patients manage with such tasks.

You are free to say yes or no to any part of this at any stage. You will not be asked to attend hospital or your GP more than is usual. I will not ask your doctor to show me your medical records. With your permission, I may ask your doctor to confirm any facts you are unsure about regarding your medication or medical treatment.

5. What do I have to do?

Please return the enclosed reply letter in the envelope provided or to the address at the bottom of this page, or email me at camdenstudy@btinternet.com. If you are willing to take part, I will sort out an interview time and date at your convenience.

6. What are the possible benefits of taking part?

There are no direct benefits: I hope the information gained from this study can be

used in future to help improve how health services involve patients in managing their long-term conditions.

7. Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you that I keep will not include your name and address, so that you cannot be identified from it. Medical practitioners who are treating you will not be told what you say in the course of this research.

8. What will happen to the results of the research study?

The results will be published as part of an academic work in 2011: Cranfield University will hold a copy in their library. The results may also be published in academic papers and journal articles with an international audience. You will not be identified in any report or publication.

9. Who is organising and funding the research?

The research is funded by Cranfield University.

10. Who has reviewed the study?

The study has been approved by Cranfield University's Health Ethics Committee and the Camden and Islington Community Local Research Ethics Committee.

11. Contacts for Further Information

For further information, please contact Yasmin Fitzpatrick by email at camdenstudy@btinternet.com or by mail to Yasmin Fitzpatrick, Camden PCT, Room 235, 79 Camden Road ,London NW1 9ES

Thank you for taking the time to read this information.

APPENDIX E: PATIENT CONSENT FORM



CONSENT FORM

Study: how patients manage long-term health conditions

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study discussion and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary. I am free to withdraw at any time, without giving any reason, without my medical or legal rights being affected.

☐

3. I understand that the researcher will not see my medical records, but may ask my GP or hospital consultant to provide information about my medication or hospital treatment if relevant.



4. I agree to take part in the above study.



Name of Participant

Date

Signature

1 copy for participant; 1 copy for researcher.

Participant Identification Number :

APPENDIX F: STUDY PROTOCOL



STUDY PROPOSAL AND PROTOCOL

Patient knowledge and co-management of coronary heart disease (CHD)

Background and context

The NHS is currently facing an unprecedented chronic disease epidemic: according to the Department of Health, around 80% of GP consultations currently relate to chronic disease; in secondary care, chronic disease patients take up around 60% of hospital bed days. The numbers of people with chronic disease are expected to increase two to threefold by 2030. Chronic disease describes a group of lifelong non-infectious illnesses for which there is no cure, such as coronary heart disease, stroke, depression, chronic obstructive pulmonary disease, diabetes and some cancers. This study will focus on patients with a history of CHD.

Treatment of CHD depends on the specific form of the disease in each patient, but effective treatment always includes preventive lifestyle changes. Medications, such as blood pressure reducing medications, aspirin and the statin cholesterol-lowering drugs may be prescribed. In some circumstances, surgery or angioplasty may be warranted to reopen, repair, or replace damaged blood vessels.

Much policy discussion about CHD focuses on reducing the burden it places on the NHS economy (Department of Health, 2004) and the practical necessity of increasing

patient involvement in the management of their condition. What is less clear is how this will affect the relationship between chronic disease patients and their health providers, and how it will change patient access to clinical and health organisation knowledge and information. The healthcare literature is only starting to focus on how patients understand and, to a much lesser extent, themselves produce knowledge about their chronic disease in response to treatment.

Research objectives

This study will examine firstly, how patients with CHD find out about, understand and manage their long-term illness; and secondly whether patients involved in managing different types of CHD produce new knowledge or understanding about their treatment or condition in the course of self-management that has wider implications for the clinical management of CHD.

Study protocol

Patients will be invited to participate by the Principal Investigator, Yasmin Fitzpatrick, either verbally or in writing, using the information sheets and invitational letters appended.

The Principal Investigator (PI) will take face-to-face written consent from each patient in the study, leaving at least 24 hours between providing the patient with written information about the study and asking the patient to sign the consent form. The PI will provide a verbal explanation of the study to each volunteer prior to the first interview and at any stage during the study on request. Face-to-face interviews with volunteers will be held in safe venues to be arranged by the PI.

Patient activities concerning self-management of their condition, such as taking medication or self-monitoring blood pressure, may also be observed as well as discussed with them. Observation will only take place if the patient gives express

permission. Where observation takes place in the presence of healthcare staff, their permission will also be sought.

Confidentiality

Interviews may be recorded on audio-equipment with the volunteer's consent and written notes will also be taken. All data will be anonymised before being transcribed or entered onto a computer. All information will be securely stored in a locked cupboard and will be destroyed three years after the PhD work is completed.

Anonymised results will be disseminated to PhD supervisors in the form of a report prior to inclusion in the final PhD document.

Design

This is a qualitative study of up to 40 patients with CHD, using a grounded theory approach, involving semi-structured interviews over a 12-month period.

Inclusion criteria

English-speaking CHD patients 30 years of age or over; patients able to give consent; patients with CHD will be defined as such on the basis of an existing clinical diagnosis.

Exclusion criteria

Patients unable to give consent; patients under the age of 30; patients unable to speak sufficient English to understand oral questions (due to a lack of availability of interpreters for the study duration); patients considered by either their clinician or the principal investigator to be too unwell to take part in an hour-long interview,.

Participants

In addition to the above criteria, the study will seek to include:

- 1 up to 40 patients with cardio-vascular disease, in any combination of primary or secondary outpatient care in the Camden PCT catchment area.
- 2 M and F patients
- 3 patients falling within three age ranges: 30-44, 45-64, 65 and over
- 4 patients with a range of educational attainment: none, GCSE/O/CSE, A levels, university degree
- 5 patients with the following ethnic identities: white English, Afro-Caribbean, Asian, white Irish

Patient safety

The study involves patient observation and interview; no patient will be asked to perform any activity they would not normally perform. The patient interviews will examine how much patients understand about their condition and where they seek further information, as well as examining any knowledge patients themselves may have generated about their condition in the course of managing it.

It is possible that a patient may choose to disclose something that embarrasses or upsets them. The following procedures will be employed: when arranging the interview, I will enquire about the availability of a friend, family member or carer for any person who thinks they might like or need such support. I will ensure I have the name, address and phone number of the GP of all patients interviewed.

At the start of the interview, I will tell the patient that they can terminate or reconvene the interview at any time and that they do not have to talk about anything they do not wish to tell me. I will not proceed with any interview if there are reasonable grounds to suspect that to do so would have an adverse effect on the patient.

If an interviewee appears to require emotional support during or after interview, I will try to ensure that a close friend, carer or family member is made aware, and especially

that the patient is not left alone in an emotional state. If any patient is unduly upset, or behaving in a manner that causes serious concern for their mental or physical wellbeing, I will inform their GP as a matter of urgency.

The British Sociological Association's Statement of Ethical Practice for conducting Research with Human Participants has been referred to in the completion of this protocol and will be used to guide the research process (Ref: www.britsoc.co.uk).

The principal investigator Yasmin Fitzpatrick has long experience of both the practice and the ethical implications of conducting expert and non-expert interviews, due to her work as a television documentary producer and commissioning editor for the BBC and Channel 4. She also worked as a project manager in Patient Services at Barts and the London NHS Trust.

A brief explanation of the Grounded Theory research method

Grounded Theory (GT) is a systematic generation of theory from data that contains both inductive and deductive thinking. One goal of GT is to formulate hypotheses based on conceptual ideas.

What differentiates grounded theory from much other research is that it is explicitly emergent. It does not test a hypothesis: the aim is to discover the theory implicit in the data. As such, it is a good method for conducting exploratory research.

APPENDIX G: SEMI-STRUCTURED INTERVIEW GUIDE

Semi-structured interview guide

To cover the following topics

1.
 - a) Go through information sheet and ask for questions.
 - b) Explain forms to be filled in: consent and demographic info.
 - c) 'Try to be honest' discussion

Knowledge of condition

2.
 - a) Can you explain your health condition to me?
 - b) When diagnosed?
3.
 - a) Do you know what caused your illness?
 - b) Who told you that?
4.
 - a) Are you taking any prescription medications for your heart condition?
 - b) How many, how often?
- c) Any other medication for anything else? Interaction problems?

Attitude to medical advice

5.

Do you take your medication exactly as the doctor prescribed? Why not?

1 Do not want to take medication at this time

2 Side-effects caused by medication

3 Medication not working

4 Ran out of medication

5 Too costly / financial constraints

6 Don't think I need it

Other

Recall of medical advice

6.

Did the doctor give you any other medical advice?

7.

a) Has a doctor or other health professional ever suggested:

... limiting your daily salt intake?

... eating certain foods such as fruits and vegetables, fish or lean meats, foods high in fibre or foods low in fat?

... participating in physical activity or exercise?

... controlling or losing weight?

... quitting or cutting down smoking?

... limiting alcohol consumption ?

... reducing your level of stress?

b) How did the doctor give you this advice? Via leaflet, in writing, verbally?

Self-management

8.

a) Do you know what your last BP reading was?

b) Do you know what your target blood pressure is?

9.

a) Do you know your cholesterol level?

b) Do you know what your target level is? (5.2)

10.

a) Do you know your weight?

b) Your ideal weight?

11.

Do you monitor your own blood pressure outside of a health professional's office or medical clinic?

1 Daily

2 Weekly

3 Monthly

4 Three to four times a year

5 Once a year

6 Less than once a year

7 Do not monitor own blood pressure

12.

Do you report your BP measurements to your doctor or nurse?

13.

If you think your BP is too high, what do you do?

1 Contact a doctor or other health professional

2 Continue to monitor your blood pressure to see if it is consistently high

3 Make changes to your lifestyle (e.g. diet, exercise, lose weight, etc.)

4 Rest

5 Go to the hospital emergency room

6 Increase your medication

7 Do nothing

8 Other

9 Not applicable - blood pressure has never been too high

14.

Has a doctor or nurse ever shown you how to use a BP measuring device?

15.

Where do you measure your BP?

- 1 At home
- 2 Pharmacy
- 3 Workplace
- 4. Gym or fitness facility

16.

When was the last time you had your BP measured by a health professional? Was it:

- a) less than 1 month ago?
- b) 1 month to less than 3 months ago?
- c) 3 months to less than 6 months ago?
- d) 6 months to less than 1 year ago?
- e) 1 year to less than 2 years ago?
- f) 2 or more years ago?
- g) Never had blood pressure measured by a health professional

17.

Do you manage any other treatments yourself?

18.

- a) How well do you think you manage your health generally? Very well/quite well/not very well/badly
- b) How well do you think you manage your specific health condition? Why?

19.

Could you do more? What?

20.

Do you feel that you have a plan that you follow to help you manage your condition? What is it? Would you like one?

21.

- a) Do you think there is more that you think you could do for yourself without involving the GP in the same way?

b) Would you like to?

22.

Do you think your doctor would like you to manage your health more for yourself?

23.

In general, do you feel that you have enough information to help you manage your condition?

24.

a) Would you like more information when you visit your doctor/nurse? What?

b) Would you like to see the screen the doctor looks and have it explained?

c) Would you like to have easy access to your own health records? Why?

24.

a) Have you ever received training in managing your condition?

b) How would you like to receive information or training in the future?

1 Book, pamphlet, or brochure

2 CD, DVD, or video tape

3 Package insert included with medication

4 Advice given during a medical appointment

5 Support group

6 Course or class

7 Media, for example, television, radio, newspapers, or magazines

8 Internet

9 Other

25.

What have you learned about managing your condition that it might be useful for other patients to know?

26.

With the experience you now have, is there anything you think the NHS should do differently?

Values: trust

27.

Who did you turn to when you found out about your condition? Why?

28.

a) Who do you get your advice and information from about your condition?

b) Anywhere else?

c) Now let me read you a list about where you might get information from– choose as many answers as you like.

a. NHS staff :

GP

Nurse

Hospital consultant

Other

b. Leaflets/written information

NHS leaflets

Leaflets from drug companies

Leaflets from self-help groups or campaigning groups

Magazine or newspaper articles

c. Online info:

NHS direct

NHS website

Other website

d. Support group

Patient/carer chatroom – do you belong to a group of any kind?

e. Media

Radio or tv phone-in, newspapers, news

f. Friends and family

Discuss outside family or too private?

g. Other people with condition

People you already knew

People you met as a result of the condition

29.

Which of these sources of information do you trust most? Why?

30.

Which of these sources is most likely to be right?

31.

Does any information you read contradict what your doctor tells you? What do you do?

32.

a) Do you belong to any kind of patient group? What? Why?

b) How did you find out about them?

Values: attitude to doctor

33. When you visit your doctor, how often do you do the following:

1.Never/ 2. almost never/ 3. sometimes/ 4. fairly often/ 5. very often/ 6. always

a) Prepare a list of questions

b) Ask questions about the things you want to know and things you don't understand about your treatment

c) Discuss personal problems that may be related to your illness

34.

In the last 6 months, how many times did you visit your doctor?

35.

How many times did you visit hospital emergency dept?

36.

How many times were you kept in hospital?

37.

In the past 12 months, have you seen, or talked to a health professional about your heart condition?

38.

a) Do you think your doctor is always right? Examples? b) What does your GP do well/badly?

Values: alternative sources of treatment

39.

Do you ever try a treatment recommended by people other than your doctor?

40.

a) Do you ever do things differently from what is prescribed?

b) Do you ever ignore or disagree with advice from doctor or nurse?

41.

a) Do you practice any kind of alternative therapies?

b) Do you tell the doctor? Why/not?

Self-reported outcome measures

42.

How do you feel about your treatment? Does it work for you? Does it make you feel better?

43.

a) What do you regard as successful management of your condition?

b) How would you measure it?

44.

- a) If you had to choose one thing about your health that you want your medical treatment to fix or improve, what is it?
- b) How would you measure/capture it?

Values: on concept of health

45.

- a) Is increased self-management for patients with LTCs a good idea?
- b) Why do you think it is being encouraged now?

Closing questions

51. Have I missed anything out that you think we should talk about?

52. Name of GP practice

Thank you for taking part

b. All answers will be used anonymously

c. All discussion confidential

d. please fill in forms and take one for yourself if you wish

e. please take an information sheet - my contact details are on sheet

APPENDIX H: CAMDEN GP QUESTIONNAIRE

All answers are confidential and all data will be anonymised. Once completed, please save this document and email back to:

camdenstudy@btinternet.com or post to: Yasmin Fitzpatrick, Camden Study, 15 Ferndale Rd, London SW4 7RJ. Thank you.

NB: to type directly onto the document: look above the document on screen – it may read 'Security Warning Some active content has been disabled'. If so, click on the **Options** button beside the statement and then click on **enable this content**.

Please try to answer accurately, in terms of how you view your current situation.

1. Do you ask overweight CHD patients to try and reduce their weight? How often? Do you offer them any aids?

	Often	Sometimes	Rarely	Never
2. <i>Do overweight CHD patients request your help in trying to reduce their weight?</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	In writing	Verbally	I don't	Other
3. How do you give patients with CHD information about how to manage their own care at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Please describe briefly in box below

Yes

Plan to in
next year

Plan to in
future

No plans to
do so

4. Do you provide CHD patients with easy access to their medical records?

○

○

Yes

No

5. Do you offer to communicate with your CHD patients by email regarding ongoing treatment?

Every 6 mths	Every 12mths	Less often	Never
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6. How often do you receive data on:

a) CHD patient clinical outcomes

(eg. %age patients with satisfactory BP readings)

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

b) patient satisfaction /feedback

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------

Yes

No

7. Do you use this data to improve services?

☐☐

If yes, please give some examples in box below or continue at end of survey

8. Are there any CHD programmes in place to target specific population groups in your catchment area?
What are they?

9. What barriers to effective CHD management have you experienced?

10. What might help you improve the management of CHD in your practice?

11. What might help patients improve their own management of CHD?

12. Do you encourage self-management for CHD patients eg. home BP checks, weight management, tele-health applications? If so, what?



13. Do you think an increased emphasis on patient self-management of CHD would positively affect patient health outcomes?



14. What outcome measures do you think best reflect the efficacy of the treatment dispensed to CHD patients?



15. What outcome measures do you think best reflect CHD patient expectations from long-term treatment?

16. If patients were to share access to all medical data held on them and input their own data on their health record, what if anything would you want to change about the form or content of health records held in your practice?

17. Do your CHD patients ever disagree with or disregard the treatment you propose for managing their condition?

Often

Sometimes

Rarely

Never

☐☐☐☐

18. What are the areas of treatment these patients are least likely to comply with?

19. To your knowledge, do your CHD patients ever use alternative therapies or treatments you have not prescribed?

Often

☐

Sometimes

☐

Rarely

☐

Never

☐

20. If so, what do you do, if anything?

21. Is there a system for feeding back patient suggestions for changes or improvements to their care to your practice manager, PCT or anyone else? If so, please describe briefly how it works:

22. With what aspect of their self-care do you think CHD patients need more support? And who or what could best assist them?

23. What changes would help the NHS manage the projected escalation in numbers of people presenting with long-term conditions?

Finally, three demographic questions:

i. How old are you?

Under 35

☐

35-49

☐

50-64

☐

65 or older

☐

ii. Are you:

Male

☒

Female

☐

iii. Name and practice address (optional)

This data is for follow-up purposes and will not
be used to identify doctors, patients or surgeries

Thank you for taking the time to participate in this study

Please save your document changes and email to: camdenstudy@btinternet.com or post this form asap
to:

Yasmin Fitzpatrick, Camden Study, 15 Ferndale Road, London SW4 7RJ

